



CLINICAL REPORT

Out-of-Home Placement for Children and Adolescents With Disabilities

abstract

FREE

The vast majority of children and youth with chronic and complex health conditions who also have intellectual and developmental disabilities are cared for in their homes. Social, legal, policy, and medical changes through the years have allowed for an increase in needed support within the community. However, there continues to be a relatively small group of children who live in various types of congregate care settings. This clinical report describes these settings and the care and services that are provided in them. The report also discusses reasons families choose out-of-home placement for their children, barriers to placement, and potential effects of this decision on family members. We examine the pediatrician's role in caring for children with severe intellectual and developmental disabilities and complex medical problems in the context of responding to parental inquiries about out-of-home placement and understanding factors affecting these types of decisions. Common medical problems and care issues for children residing outside the family home are reviewed. Variations in state and federal regulations, challenges in understanding local systems, and access to services are also discussed. *Pediatrics* 2014;134:836–846

INTRODUCTION

Most children and adolescents with developmental disabilities and chronic health conditions live and thrive at home with their families. However, some of them reside outside their family homes. They usually live in congregate care settings in which 4 or more people receive care for a variety of medical, psychiatric, behavioral, and developmental issues. In the past 35 years, the number of children and adolescents living in residential settings has decreased significantly. In 1977, 36% of residents in state facilities were between 0 and 21 years of age. This total does not include children and youth in residential facilities operated by other entities, such as private corporations and religious orders. There has been a significant decrease in the number of residents living in congregate care settings since that time. However, in 2010, 4% of those living in congregate care were between 0 and 21 years of age; approximately one-third of these subjects ($n = 7926$) were younger than 14 years of age.¹ The shift from people with disabilities living in care centers to community living was accelerated by the Olmstead Act of 1999 (http://www.ada.gov/olmstead/olmstead_about.htm), which stated that unjustified segregation of persons with disabilities violates Title II

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KEY WORDS

children and youth with special health care needs, intellectual and developmental disabilities, out-of-home placement, pediatric skilled nursing facilities

ABBREVIATIONS

AAP—American Academy of Pediatrics
IDD—intellectual and developmental disability
SNF—skilled nursing facility
SSI—Supplemental Security Income

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of the Americans with Disabilities Act. Furthermore, the Olmstead Act mandated that persons with disabilities be provided appropriate and reasonable accommodations for community-based services. Within that context, 1 goal of the Healthy People 2010 program was to “reduce to zero the number of children aged 17 and younger living in congregate care facilities.” The revised goal of Healthy People 2020 is more realistic, aiming to “reduce the number of children and youth aged 21 years and under with disabilities living in congregate care residences” by 10% or from nearly 29 000 children in 2009 to 26 000 children in the next decade.² In 2000, the Centers for Medicare & Medicaid Services reported that there were 4886 children with special health care needs in the United States residing in skilled nursing facilities (SNFs), of whom 1222 had intellectual and developmental disabilities (IDDs).³ Intellectual disability refers to a group of conditions in which there is limited cognitive capacity, significantly reduced adaptive skills, and onset before 18 years of age. Developmental disability is a severe and chronic disability that may affect cognitive and/or physical functioning and has an onset before 22 years of age.⁴ It has been postulated that placement of children and youth (referring to adolescents) with IDDs into SNFs occurs when families are not able to obtain adequate community-based care and support. However, the reasons for placement of children in various types of residential facilities are complex and multifaceted.⁵

In 2005, the Council on Children With Disabilities of the American Academy of Pediatrics (AAP) endorsed the goals of Healthy People 2010, supporting the importance of permanency planning as a means to care for children with special health care needs in the family home.⁶ In response to a published editorial contesting the notion that no

children should be placed in congregate settings,⁷ the Council on Children With Disabilities responded by indicating that, although the AAP endorsed Healthy People 2010, the council did not endorse the specific goal of eliminating congregate care. The council called on the AAP to develop a policy regarding the role of congregate care for children with special health care needs.⁸

The goal of the present report was to review the subject of pediatric congregate care, including the characteristics of children and youth who may be admitted to congregate care centers, definitions of residential placement options, typical reasons for placement, and suggestions for pediatricians who work with children and youth whose families may consider out-of-home placement. This report focused on young people who generally are nonverbal, nonambulatory, and dependent for most or all activities of daily living. Most of these young people have severe to profound intellectual disability, and some have no ability to interact with their environment. Some of the children and adolescents who reside in these settings for respite services or postoperative or rehabilitation care may have less severe presentations or may present with complex and chronic medical conditions, making them totally dependent on others for daily care.

CHILDREN AND YOUTH WITH IDD AND/OR SPECIAL HEALTH CARE NEEDS

Much has been written and acknowledged about the benefits of providing home- and community-based supports for children, adolescents, and adults with a wide range of disabilities and special health care needs.^{9,10} As a result, changes in public and professional awareness, values, policies, funding sources, and programmatic supports have occurred. With these changes, the

vast majority of children and adolescents who require assistance with all or most daily living skills and ongoing skilled nursing care live with their parents.^{1,11} However, children and youth with significant disabilities and special health care needs may have multisystem medical problems that often worsen over time. Children may require care for neurologic, pulmonary, orthopedic, gastrointestinal, endocrine, metabolic, and other medical problems.¹² Although there are home health care agencies and other community-based supports for families, there is substantial variability of resources depending on jurisdiction, funding, diagnosis, and other factors. In addition, not all families have the housing resources or personal capacity to care for children with special needs.

In 2010, approximately one-third of children, adolescents, and adults with IDDs nationwide were on waiting lists for a variety of community-based services and supports.¹¹ At any time, there are more families waiting for services for their children who have technological needs than there are persons available to provide these services, and the necessary funding is not consistent or guaranteed, leaving families to care for their children without professional support. Some children currently residing at home receive more technically demanding care than is possible in many SNFs, including ventilation and intravenous nutrition, placing substantial responsibilities and stresses on families and home life.¹³ The decision to provide this type of care at home may be a choice or a necessity, given some of the financial, resource, and policy constraints.

TYPE OF RESIDENTIAL FACILITIES

There is no consistent definition for the different types of congregate care facilities. The definitions vary state by state, and the term “nursing home”

does not have a formal and generally accepted definition. Nursing homes vary in types of services provided, with “skilled” generally being used to indicate a higher level of nursing care. However, this distinction is not universal, and statistics provided do not clearly make that differentiation. SNFs and intermediate care facilities are places where people live; therefore, these subjects are usually referred to as “residents” rather than patients. Although residents may leave, such as for a visit to their family home, there usually is not an anticipation of a “discharge date.” This type of arrangement differentiates these facilities from transitional settings, residential schools, respite centers, rehabilitation hospitals, and other settings where children may stay for specified periods of time while receiving care related to their disabilities or their medical needs.

SNFs

SNFs, commonly referred to as nursing homes, care for individuals who require 24-hour skilled nursing procedures on a daily basis, regardless of specific diagnosis or etiology, for their medical problems. Pediatric SNFs care for children, youth, and some adults with special health care needs, most of whom also have IDD. Some facilities require residents to have severe to profound intellectual disability for admission. Services provided include ongoing nonoral feeding (eg, gastrostomy or jejunostomy tube feedings), medication administration, suctioning, and skilled assessments. Not every SNF provides the full gamut of technically advanced nursing care, such as tracheostomy care, mechanical ventilator support, intravenous fluid or nutrition, or dialysis. The medical complexity of children admitted to SNFs has increased over the years. In many SNFs, direct patient care is primarily provided by certified nursing assistants

under the direction of registered, licensed practical, or vocational nurses. Physicians make regular rounds, the frequency of which varies between states and even between facilities within the same state; physicians generally are not present on a daily basis. Many facilities also provide short-term respite care, either on a planned or an emergency basis.

The provision of physical, occupational, speech, and behavioral therapies is variable. Specific standards for environmental conditions, staffing levels, and physician certification for facilities caring for children do not exist at a federal level, although standards do exist for SNFs in general. In some states, children can only be admitted to pediatric facilities; in others, they may be admitted to general facilities with or without specific waivers.

Intermediate Care Facilities

Intermediate care facilities are residential facilities that provide daily care for subjects who require care and supervision but who do not require 24-hour-per-day skilled nursing. These services include assistance with activities of daily living, such as feeding, incontinence care, dressing and bathing, medication administration, and safety supervision. They usually do not provide parenteral medication or nonoral feeding.

Acute Care or Specialty Hospitals Providing Long-term Care

Provision of long-term care in this type of setting is a relatively new concept. A physician provides daily assessment and care for patients who require a hospital level of treatment on a long-term basis. This care may include mechanical ventilator management with frequent adjustments, frequent modifications to daily medication regimens, parenteral fluids, and medications, dialysis, complex wound care, and other

medically complex interventions to patients who are not expected to improve in the short-term.

Transitional Facilities

Transitional services are sometimes located within hospital settings and SNFs, although these settings may also be freestanding and located within residential buildings. They primarily provide a transition for patients with skilled care needs who are being discharged from the hospital before returning home. For example, care may be provided to a child with a new tracheostomy while training the family in its use and developing the plan for home care. These facilities also may provide care for children and adolescents with multiple medical needs on a respite or temporary basis or after a change in medical condition, such as postoperative orthopedic surgery care. There is not a consistent definition or licensing for transitional facilities. Although, implicitly, patients are cared for in these settings for relatively short periods of time, the length of placement may vary.

Rehabilitation Hospitals

Rehabilitation hospitals are not congregate care facilities; they provide short-term hospital care with nursing, medication management, and intense rehabilitative therapies. Some SNFs for adults use the term “rehabilitation center,” and some skilled care facilities for adults provide what is termed “subacute rehabilitation,” which implies treatment intended to improve function but at a level less intense than that provided in a rehabilitation hospital. It is unusual for this type of facility to be available for children.

Residential Schools

Some children and adolescents are cared for in residential schools that provide expertise and educational curricula for individuals with specific

health conditions or disabilities. Most of these settings are for children and youth with long-term behavioral or psychiatric problems, although some exclusively serve children with physical or developmental disabilities. The level of nursing and medical care provided within these programs varies. These settings do not provide the same level of care provided in SNFs. The children usually return to their family home during school vacations. These schools may be private or public programs.

Medical Group Homes

In some states, medical group homes have replaced other forms of technologically advanced residential facilities. These homes have providers who typically care for relatively small numbers of patients in adapted single-family homes within residential neighborhoods. Medical group homes may provide nursing care at the level of the SNF.

All of these types of facilities must follow state and/or federal regulations. Skilled care facilities must comply with federal regulations.¹⁴ However, regulations for level of care, environmental safety, staff ratios, and types of residents served, as well as payment sources, vary state by state.¹⁵ Admission is regulated and cannot occur simply by parental or physician request. Specific admission criteria and processes for admission vary by state. In general, individuals younger than 22 years are not able to be placed in adult SNFs, and adults are not admitted to pediatric SNFs. However, there are situations in which subjects obtain waivers to allow for exceptions to these policies. Many states also now allow children to be present in adult SNFs, using “intergenerational models.”

TRANSITIONS TO ADULTHOOD IN CONGREGATE CARE SETTINGS

As young people with significant IDD and special health care needs reach

adulthood, many remain in pediatric facilities because of insufficient community resources to address issues specific to their disabilities and health problems, including insufficient expertise of medical and nursing staff in caring for adults with IDDs in SNFs. In addition, there may be regulations prohibiting the placement of subjects with IDDs in SNFs for adults who are medically fragile but without these types of disabilities. This lack of adequate care options often creates extremely difficult situations for young adults with profound IDDs who have been in residential placement since early childhood and are now over age for the licensed facility where they have always received care. Although some patients remain in the pediatric SNF, the medical and nursing staff may not have experience in the recognition and management of adult medical conditions (eg, ischemic heart disease). In addition, as adults with IDDs age, many develop special health care needs that may not be adequately met in nonskilled care facilities or at home with aging parents.

CHARACTERISTICS OF CHILDREN WHO LIVE OUTSIDE THE FAMILY HOME

Decades ago, most children referred to residential placement had intellectual or developmental disabilities; some did not have significant medical problems.^{1,2} Certain medical interventions, such as use of feeding tubes and positive-pressure ventilation, were not commonly used in long-term care facilities, with the exception of respiratory care for children with polio. Many families also were encouraged to place their infants with Down syndrome into institutional settings. With the dramatic changes in living situations and community supports for subjects with disabilities over the past 40 years, it would be extremely

difficult to place an infant with Down syndrome who did not have associated chronic complex conditions into an institutional setting today. Home care waivers that allow Medicaid funding for long-term nursing care provided at home, including for families who might not otherwise be financially eligible for Medicaid (eg, Katie Beckett waivers), began at approximately the same time. The idea, and then the expectation, that long-term sophisticated medical, rehabilitative, and technological care would be provided for children with complicated disabilities co-occurred with support for home care, mandatory eligibility for special education, and the recognition that families of children with developmental disabilities thrived when family members remained together.

The Developmental Disabilities Assistance Bill of Rights Act, section 102,¹⁶ defines developmental disability as a severe, chronic disability that is the result of mental and/or physical impairments, occurs before 22 years of age, is chronic in nature, and results in significant limitations in at least 3 major areas of functioning. Children from birth through age 9 years do not require 3 or more major areas of limitation in the presence of significant developmental delays or specific congenital or acquired conditions, if there is a high likelihood of meeting all criteria later in life if their needs are not addressed. These limitations result in the need for a number of different services and supports for children, youth, and adults.¹⁷ Importantly, most people with developmental disabilities do not have medically complex conditions or chronic illness. There is variability in how states define disability for different types of services, as well as how services are provided to children. Medical diagnoses pertaining to disability generally do not

correspond to educational definitions of disability.¹⁸ Children and adolescents who are medically fragile and/or technology dependent are supported by government, educational, and fiscal programs that do not apply to adults, leading to a significant step-down in services and available supports when reaching adulthood.

Many children and youth who receive skilled care have problems that were acquired or are later-presenting medical conditions, such as acquired brain injury, spinal cord injuries, leukodystrophies, neuromuscular conditions, or catastrophic complications of other illnesses. Although many young individuals in skilled care facilities have severe to profound IDD and complicated medical conditions regardless of etiology, there are some children who require significant medical and technological support in the context of normal or more mildly affected cognitive skills: for example, those with neuromuscular disorders who require assisted ventilation or children and adolescents with long-term need for parenteral nutrition. Their needs for social support, education, recreation, and future planning are different from those of children with severe to profound intellectual disability. The needs of children and adolescents with life-limiting disorders (eg, leukodystrophies) or children whose parents have decided against life-prolonging treatment are also different from those of children with profound disabilities who are expected to live into adulthood.

DIFFERENCES BETWEEN HOME CARE AND RESIDENTIAL CARE

Children and adolescents in congregate care settings are cared for differently than when they are at home. The most obvious difference is that they do not usually have daily contact with parents and siblings, and their care is provided

by different people throughout the day. Families visit their children at variable frequency. Unfortunately, some children have little contact with their families. There also are greater risks of infectious diseases when individuals are in congregate care settings, despite requirements for universal precautions and immunizations.

The care of children and youth in residential settings is driven by physician orders and nursing protocols and may be more regimented than home care (eg, timing of feeding, bathing, and medication administration). Licensed personnel are required to report specific changes and to follow medical orders and facility protocols, whereas parents are free to use their own judgment. Nursing homes may have contractual or regulatory limits on what pharmacies or suppliers they can use; these restrictions may limit access to certain medications, formulas, and types of equipment. In some cases, particularly when there are concerns about the care a family is providing, the protocol-driven nature of congregate care may benefit the child. For example, Henderson et al¹⁹ found that children in residential care who received nonoral feedings demonstrated improved growth compared with children in home care, likely reflective of adherence to specific orders in residential facilities.

Children in residential care retain their rights to a free appropriate public education in the least restrictive setting, and some continue to participate in public schools. Therapy, educational, and recreational services frequently are provided within the facility. Children and adolescents in the community may have providers come into their home, or they may go out to different appointments. There may be fewer environmental barriers in a residential setting, access to multiple caregivers and equipment for lift-

ing, and protocols for care. However, although children and youth in SNFs might have access to technically easier care, round-the-clock caregivers, and an accessible environment that may facilitate recreation and community access, they have extremely limited interaction with typically developing peers. This limitation may be viewed as negative, neutral, or positive, depending on the particular family and child.

REASONS FOR PLACEMENT AND DECISION-MAKING

There have been a number of reports about the reasons for placement of a child, adolescent, or adult family member into a residential setting as well as the effects of that decision on other family members. Factors that affect placement decisions include issues related to the child or youth, family and parental attitudes, cultural practices, influence of the social environment, and the availability (or lack) of external assistance. Some individuals require more care than can be provided in most homes by most families,⁷ although it is clear that some families are able to do more than others for a variety of reasons. Families may not be able to adequately care for their child alone in the context of insufficient community resources, such as a large youth with a high spinal cord injury who is ventilator dependent and requires 2 people to turn him. In other situations, families lack the capability to organize, supervise, and manage a home care staff and may not be able to learn the assessment and technical skills to provide safe care. These decisions are difficult for families, and pediatricians may also be challenged when they believe that a loving family might not be the best provider of care for their own child. Llewellyn et al²⁰ found that parents, as a group, reported their desire to care for their child at home. Despite this

finding, decisions to place a child into a congregate care setting often were made for reasons that the parents considered to be important for the “survival” of the family as a whole.

Perceptions of social challenges also have been found to affect decisions for out-of-home placement in certain situations. In 1 study, parents who expect that their child with disabilities might be stigmatized in the community were found to be more apt to place their child in a residential setting.⁵ Similarly, Hanneman and Blacher²¹ found that the more “normative” the child’s appearance, the less likely families considered residential placement. Conversely, in this report, mothers of higher socioeconomic status and those with more children were more likely to consider out-of-home placement. Stress on the caregiver affected the consideration of placement as well as whether placement actually occurred. Interestingly, support resources and quality of life did not influence placement in this particular study. However, others have found that lack of adequate community-based disability or family support services to meet their particular needs was associated with out-of-home placement.²²

The importance of the well-being of families with children with disabilities has been explored by a number of researchers.^{23,24} Families have been found to make decisions regarding placement that are in the interest of maintaining the highest level of functioning of all family members.²⁵ However, not all families balance the demands of caring for their child with a disability similarly, as the context of other family needs may differ.²⁶ Hostyn and Maes¹⁰ evaluated families who placed their children in residential settings and divided them into 4 groups. Some families, whose children had multiple disabilities, health problems, and complex needs, tended to choose

placement so that the child could lead a comfortable life, with intensive medical and therapeutic supports. These families were also often noted to have difficulty balancing care for the child with disabilities with their other family and work demands. The authors also described families who had children with a developmental disability coupled with significant behavioral problems. These families tended to choose placement because they were not able to handle a child’s behavior, felt guilty and powerless, and were often socially isolated. Some of them also had concerns about the effects of negative behaviors on their other children. In general, children with these characteristics are not appropriate candidates for SNFs because they do not require skilled nursing procedures and they may be independent in activities of daily living. A third type of family was one in which 1 or both parents had physical or mental health problems or an intellectual disability. They also tended to have fewer educational opportunities, social supports, and available resources and were more likely to be unemployed or underemployed. The decision for out-of-home placement in these cases was found to be based on the parents’ feelings of inadequacy to care for their child. A fourth type of family was one in which the primary caregivers were divorced. Although both parents may be much involved in their child’s life, they perceived little support from others. In all groups, parental concern for the well-being of family members other than the child with disabilities was noted, and parents also voiced the belief that residential placement would better support their child with disabilities.

Parents remain the guardians and decision-makers for their children in out-of-home placement. Parents do not “sign away” their parental rights in these situations. Although parents are

the legal decision-makers, there may be limits on the choices parents can make regarding certain types of care for their children based on regulations or facility policy. People who are unable to make their own decisions at the age of majority must have guardians; usually, parents seek guardianship in this situation. Unfortunately, some parents abandon their children by not participating in decision-making and being unavailable for consent. In these cases, the facility must work with state child welfare agencies or, for individuals over the age of majority, with adult protective services or other agencies. There are some families who fulfill the responsibility for consent and decision-making although they are not involved in their children’s lives and do not visit them. Some children who are wards of state child welfare agencies also may be admitted to residential care, such as in situations in which the disability is the direct result of child abuse.

EFFECTS OF PLACEMENT

Baker and Blacher²⁷ evaluated the effects on the family of the placement of a family member with IDD into residential care. The vast majority of families reported that the placement had advantages for all involved. However, although parents of children younger than 15 years visited more frequently, they also reported the highest stress as well as the lowest marital adjustment and advantage to placement. Another study found no significant negative effect on adolescent siblings when a child with an intellectual disability resided outside the family home. The child with intellectual disability also continued to have an influence on family functioning, regardless of the place of residence.²⁵ Hostyn and Maes¹⁰ found that parents generally did not regret their decision to place their child into a residential setting.

Despite the benefits to family life that some have reported after placement in a residential setting, the decision for placement is extremely difficult for families to make.²² The family quality of life before and after placement also has been explored.²⁸ Overall, there were positive changes in the areas of emotions, freedom, and family relationships, although most parents reported continuing guilt and worry.

DURATION OF PLACEMENT

Because parents or guardians retain their parental rights, they may also terminate the placement and take their child home. This action sometimes occurs because parents regret their decision. It may also occur after a change in family circumstance, such as improved financial situation, change in marital status, or ability to access more community supports. In addition, it can occur because of changes or improvement in the child's condition (eg, tracheostomy care no longer needed).

When a child or youth returns to the family home, it is crucial to provide careful discharge planning that includes teaching parents or guardians and determining that they are ready to provide needed care. Important considerations for providing comprehensive home care for medically complex children and adolescents are necessary, as outlined in the previously published policy statement.²⁹ In addition to family training, arrangements need to be made for appropriate nursing services, home modifications, equipment, and transition to a new school program and therapy services.

WHO PROVIDES MEDICAL CARE FOR CHILDREN AND ADOLESCENTS IN RESIDENTIAL CARE?

There are federal regulations regarding the frequency of medical examinations in SNFs,³⁰ although there are no standards for medical directorships

or consultancies in these settings or for intermediate care facilities providing care for people with developmental disabilities. Medical directors can be pediatricians, neurologists, family physicians, or other medical specialists. Some facilities are part of a chain; there may be a single physician or a team of physicians with responsibilities for all the facilities. Some children and adolescents might continue to obtain routine or specialized medical care from their providers before placement. Some facilities have consulting arrangements with other specialists (eg, regular orthopedic, pulmonary, neurology, or rehabilitation medicine clinics on site), and others do not. Some may have arrangements with local acute care or specialty hospitals for inpatient care for children.

It is important for physicians acting as medical directors, primary care physicians, and consultants for children in residential placement to be familiar with their patients' specific medical conditions, which can include extremely rare disorders. They should also be familiar with the frequent complications of severe disability, including progressive respiratory insufficiency, severe musculoskeletal problems, complex seizure disorders, the requirement for tube feeding, and other gastrointestinal disorders. Physicians who act as medical directors should also understand their responsibilities as they relate to policies, procedures, and compliance with local laws, regulations, and regulatory agencies. They should understand internal and external administrative structure and responsibilities, which includes understanding of policy development with regard to safety, infection control, awareness of abuse/neglect by families or employees, reporting responsibilities, consent for treatment requirements, and other issues. Knowledge

and familiarity with issues related to palliative care and end-of-life decision-making are also an integral part of physician responsibilities.¹²

FINANCIAL SUPPORT FOR RESIDENTIAL PLACEMENT

Federal and state funds may be available to support children with severe disabilities and special health care needs to remain at home.³¹ However, it has also been noted that families of children with disabilities have disproportionate out-of-pocket expenses for the care of their children compared with the general population despite public and private insurance coverage, with lower-income families experiencing the most financial burden.^{32,33}

There has been a significant increase in federal funding to provide community support for children and youth with IDD and/or special health care needs, with diminished support for institutional settings. Additional funds for community support are sometimes provided by states, counties, and municipalities.³¹ Most children and adolescents residing in out-of-home settings become eligible for Medicaid, which continues to be a major supporter of care in SNFs across the life span. Although Medicaid coverage for SNFs for those younger than age 21 is optional for states, all states provide this benefit.³⁴ Supplemental Security Income (SSI) of children in SNFs is directed to the SNF for their care, because that is where they live. This policy is often surprising to families who have come to rely on the SSI as part of the family's income. Settings classified as schools or transitional settings do not access the child's SSI. A child with his or her own assets (eg, insurance settlements, inheritances) may not be eligible for public benefits. Private family medical insurance may also be accessed for some services,

such as therapy or care provided outside the SNF, but very few, if any, private insurance policies pay for skilled care placements. The Patient Protection and Affordable Care Act (Pub. L. 111-148) was passed in March 2013, with provisions to improve information accessibility to consumers, emphasize quality assurance and performance improvement, and prevent abuse in nursing homes.³⁵ However, payment for SNFs has not fundamentally changed under this law.³⁶ Because there may be variability in types of funding, each facility has personnel who understand funding sources and billing and should be able to provide that information to families. Educational programming for children and youth in out-of-home settings is generally funded by the school district in which the family lives. If a child attends a residential school because, as part of the individualized education plan process, the local school district has determined that it cannot meet the child's needs in a less restrictive placement, the school district may be responsible for paying for the residential services as well as the educational component. Families, even those with limited resources, may benefit from consultation with a professional skilled in financial planning and estate planning to learn how to maximize public benefits and preserve their ability to provide care and opportunities for all of their children.

Just as funding for home care is precarious in type, amount, and timing, funding for residential care also is limited. Because skilled care facilities must provide care within a strict limit of per diem Medicaid payments, they may decide that the more medically fragile children cannot be cared for adequately for the allowed amount of money. These limitations can lead to situations in which children who need more highly skilled care (eg, ventilation,

dialysis, total parenteral nutrition) will not be accepted for admission and therefore must be cared for at home, with parents providing much of the care with less supervision and fewer physical accommodations and resources than would be possible in an SNF. In essence, the parent provides unpaid skilled care at home, which, supplemented by funded home health care, provides a higher level of care than can be provided in a nursing home. In other situations, children remain in acute care hospitals for long periods of time, sometimes years. Some nursing homes raise money through philanthropy, which can supplement per diem payments for services. Nursing homes may be either for-profit or not-for-profit, and these differences can result in different payment, staffing, and other service provision.

FAMILY SUPPORT IN THE MEDICAL HOME

Families of children with significant IDD and/or special health care needs require support to obtain services, navigate complex systems of care, understand care options, and be supported in making difficult decisions that involve the entire family. The perception that professionals, such as primary care providers, expect families to care for their children at home, coupled with the lack of available support and resources, has been noted to be a source of frustration to families.²⁰ Hostyn and Maes¹⁰ also found that, even with provision of "family support," many families do not feel as if all their needs are being met. Caring for children and youth with complex needs and their families requires ongoing commitment from the primary care physician and the subspecialists who may be providing the majority of the child's medical care. Support from other health professionals, such as social workers,

can provide additional needed assistance to both families and the primary care provider. The support needed will change over time as the child's condition changes and as the family's understanding and relationship with their child evolve and grow. Ideally, the medical home model should provide this type of support; however, there are circumstances in which some parents need more care than can be provided from the medical home and in the community, given the current state of available resources.

CONCLUSIONS

Despite the fact that considerable progress has been made to support children with significant developmental and/or medical problems in the home setting, there continues to be a need for other options of care and living arrangements. The decision to have a child live away from the family home is difficult and complex. Although consideration must be given to providing each child with the best resources and support as possible, the family's needs, stressors, capacity, and relationships must also be considered. The importance of trying to support families to care for the child at home cannot be overstated. However, parents of children with significant special health care needs may, at some point, consider out-of-home placement.

GUIDANCE

1. Pediatricians who care for children and youth with medically complex needs or severe disabilities should, as part of medical home services, be aware and knowledgeable of community supports for these families. This assistance includes familiarity with respite services, programs available to provide nursing or supportive care in the

- home, and financial supports for families. State or local agencies with responsibilities for health or developmental disabilities services function as potential sources of information for families and physicians. Agencies such as The Arc (www.thearc.org) and Family Voices (www.familyvoices.org) serve as strong resources for families and medical providers. Many other national resources, such as the National Dissemination Center for Children with Disabilities (www.nichcy.org) and Disability.gov (www.disability.gov), also are helpful.
2. Pediatricians should encourage parents and caregivers to take short breaks and avail themselves of respite services. If a parent appears to be overwhelmed, anxious, or depressed, the pediatrician should express concern and be instrumental in finding support for the parent.
 3. Pediatricians should consider consultation with subspecialists who have experience in the longitudinal care of children with special health care needs for assistance with developing home care plans and consideration of long-term care options. These subspecialists might include neurodevelopmental disabilities pediatricians or child neurologists, developmental/behavioral pediatricians, specialists in the child's primary specific disorder (eg, pulmonologists, pediatric physiatrists), or palliative care specialists.
 4. Physicians should respect the family's motivation to ensure compassionate, skilled, and medically appropriate care for their child regardless of the setting in which it takes place. A decision to place a child in out-of-home care may be seen as analogous to a family's decision that a child may live with relatives or attend a boarding school. If a family wishes to consider the option of out-of-home care, the pediatrician should explore the reasons the family is contemplating placement. This type of inquiry also provides an opportunity to revisit the parents' understanding of the child's condition, prognosis, and goals of care and whether the treatment plan is consistent with those goals.
 5. Information about care options for children with complex medical problems and IDD is often available through the state health department and/or the state developmental disability agency. The physician can then learn about local facilities and the process for application and provide assistance in this process, as needed. Social work assistance, if available, can assist in accessing information and providing support to families. Personnel from the state agency responsible for screening patients referred for placement should also be available as a resource. They often require an update on the child's medical condition, including up-to-date immunizations, physical examinations, vision and hearing assessments, screening for infectious conditions, a recent psychological assessment, and some laboratory examinations for consideration of admission.
 6. The pediatrician should advise the family to visit all the possible facilities being considered, learn about the medical care provided within the facilities, meet the actual direct care providers, and make certain that the facilities meet all the state guidelines. Families of children who are living in the facilities can be excellent sources of information. Office- and hospital-based social workers also may be able to provide additional support and information to families.
 7. The pediatrician should remain available to resume care of the child when he or she is home for visits or returns home on a permanent basis and be available to the medical and nursing staff of the facility when the child is a new resident and the caregivers are not yet familiar with the child's usual condition. Some pediatricians may also continue to provide primary care for the child in a residential setting. It is important that lines of communication be clear; the facility might have policies that restrict orders to the medical director or nursing home medical staff. Direct, concise, person-to-person communication from the primary pediatrician chosen by the parents and medical director of the facility is crucial if shared care is desired by the parent and agreed to by the pediatrician and the medical director of the facility. A portable medical summary, as discussed in the AAP policy statement on transition,³⁷ provides an important mechanism to share medical records. Support for the parents' efforts to ensure safe, compassionate, and adequate care for their child is crucial. The support needed by the family is likely to change over time as the parents' role as direct caregivers diminish and as the child matures and his or her needs also change.
 8. Pediatricians may find it useful to educate themselves about local, state, and/or federal issues to support children and youth with complex medical and developmental needs. Pediatricians, individually and through the national and state chapters of the AAP, can endorse policies and legislation that support funding programs for children

with special health care needs and their families. Policies that support children and adolescents who are medically fragile or have disabilities should recognize the diversity in this population, their families, and the communities in which they live. Additional studies are needed to better evaluate the different models of care, health and developmental outcomes of children and youth who have lived or are living in residential care, options available to children who leave or age out of home care, and quality indicators in SNFs. Pediatricians should be involved in the development of policies that guide medical care for children and adolescents in all settings and should advocate for registries of those living in congregate care settings.

9. If parents require assistance exploring issues about guardianship,

health care proxy, or power of attorney as a child reaches the age of majority, pediatricians can refer to The Arc for basic guiding principles (www.thearc.org/page.aspx?pid=2351). Because there is variability based on the state in which a family resides, families may also need to seek the assistance from state disability agencies and legal counsel.

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REFERENCES

1. Larson S, Ryan A, Salmi P, Smith D, Wuorio A. Residential Services for Persons With Developmental Disabilities: Status and Trends Through 2010. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Available at: rtc.umn.edu/risp/docs/risp2010.pdf. Accessed June 5, 2014
2. Healthy People 2020. Available at: www.healthypeople.gov/2020. Accessed June 5, 2014
3. Wall Street Journal examines nursing home care for children with disabilities. Medical News Today. July 2, 2007. Available at: www.medicalnewstoday.com/articles/75631.php. Accessed June 5, 2014
4. National Institutes of Health. Fact sheet: intellectual and developmental disabilities. Available at: <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=100>. Accessed June 5, 2014
5. Green SE. The impact of stigma on maternal attitudes toward placement of children with disabilities in residential care facilities. *Soc Sci Med*. 2004;59(4):799–812
6. Johnson CP, Kastner TA; American Academy of Pediatrics Committee/Section on Children With Disabilities. Helping families raise children with special health care needs at home. *Pediatrics*. 2005;115(2):507–511
7. Eggerding C, Grossberg R, Smith K. Congregate care settings. *AAP News*. 2005;26(11):37
8. Kastner TA, Johnson CP, Sandler AD, Lipkin PH. Family-based alternatives. *AAP News*. 2005;26(11):37
9. Stancliffe RJ, Lakin KC. Longitudinal frequency and stability of family contact in institutional and community living. *Ment Retard*. 2006;44(6):418–429
10. Hostyn I, Maes B. Parents' perspectives on grounds for out-of-home placement of young children with disability. *Br J Dev Disabil*. 2007;53(2):131–146
11. The Arc. Still in the shadows: a report on family and individual needs for disability supports (FINDS), 2011. Available at: <http://thearc.org/documents.doc?id=3672>. Accessed January 19, 2014
12. Friedman SL. Medical problems affecting life and lifespan. In: Friedman SL, Helm DT, eds. *End-of-Life Care for Children and Adults With Intellectual and Developmental Disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2010:53–73
13. Wang KW, Barnard A. Technology-dependent children and their families: a review. *J Adv Nurs*. 2004;45(1):36–46
14. Medicare program; prospective payment systems and consolidated billing for skilled nursing facilities for 2014. *Fed Regist*. 2013; 78(151):47936–47973
15. Kane RA, Cutler LJ. *Nursing Home Regulations Plus*. Minneapolis, MN: University of Minnesota; 2011. Available at: www.hpm.umn.edu/nhregsplus. Accessed June 5, 2014
16. Administration on Intellectual and Developmental Disabilities. *Developmental Disabilities Assistance and Bill of Rights Act of 2000*. Washington, DC: Administration for Community Living, US Department of Health and Human Services; 2013. Available at: http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p2_tl_subtitleA.aspx. Accessed August 23, 2014

17. National Council on Disability. *Rising Expectations: The Developmental Disabilities Act Revisited*. Washington, DC: National Council on Disability; 2011
18. National Dissemination Center for Children with Disabilities. IDEA—The Individuals with Disabilities Education Act. Washington, DC: National Dissemination Center for Children with Disabilities; 2012. Available at: <http://nichcy.org/laws/idea>. Accessed June 5, 2014
19. Henderson RC, Grossberg RI, Matuszewski J, et al. Growth and nutritional status in residential center versus home-living children and adolescents with quadriplegic cerebral palsy. *J Pediatr*. 2007;151(2):161–166
20. Llewellyn G, Dunn P, Fante M, Turnbull L, Grace R. Family factors influencing out-of-home placement decisions. *J Intellect Disabil Res*. 1999;43(pt 3):219–233
21. Hanneman R, Blacher J. Predicting placement in families who have children with severe handicaps: a longitudinal analysis. *Am J Ment Retard*. 1998;102(4):392–408
22. Mirfin-Veitch B, Bray A, Ross N. “It was the hardest and most painful decision of my life!” Seeking permanent out-of-home placement for sons and daughters with intellectual disabilities. *J Intellect Dev Disabil*. 2003;28:99–111
23. Kersh J, Hedvat TT, Hauser-Cram P, Warfield ME. The contribution of marital quality to the well-being of parents of children with developmental disabilities. *J Intellect Disabil Res*. 2006;50(pt 12):883–893
24. Glidden LM, Billings FJ, Jobe BM. Personality, coping style and well-being of parents rearing children with developmental disabilities. *J Intellect Disabil Res*. 2006;50(pt 12):949–962
25. Eisenberg L, Baker BL, Blacher J. Siblings of children with mental retardation living at home or in residential placement. *J Child Psychol Psychiatry*. 1998;39(3):355–363
26. Haveman M, van Berkum G, Reijnders R, Heller T. Differences in service needs, time demands, and caregiving burdens among parents of persons with mental retardation across the life cycle. *Fam Relat*. 1997;46:417–425
27. Baker BL, Blacher J. For better or worse? Impact of residential placement on families. *Ment Retard*. 2002;40(1):1–13
28. Werner S, Edwards M, Baum NT. Family quality of life before and after out-of-home placement of a family member with an intellectual disability. *J Policy Pract Intell Disabil*. 2009;6(1):32–39
29. Elias ER, Murphy NA; Council on Children with Disabilities. Home care of children and youth with complex health care needs and technology dependencies. *Pediatrics*. 2012; 129(5):996–1005
30. Fogg R. *Nursing Home Regulations. Survey, Certification, Enforcement Manual*. Washington, DC: Thompson Publishing Group; 1995
31. Braddock D, Hemp R, Rizzolo MD, Haffer L, Tanis ES, Wu J. State of the state in developmental disabilities. University of Colorado. Available at: www.cu.edu/ColemanInstitute/stateofthestates. Accessed June 5, 2014
32. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics*. 2004;114(1):79–85
33. Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. *Arch Pediatr Adolesc Med*. 2005;159(1):10–17
34. Center for Medicare and Medicaid. Nursing facilities. Available at: www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Nursing-Facilities-NF.html. Accessed June 5, 2014
35. Kaiser Commission on Medicaid and the Uninsured. Implementation of Affordable Care Act provisions to improve nursing home transparency, care quality, and abuse prevention. Available at: www.canhr.org/newsroom/newdev_archive/2013/ACA%20Nursing%20Home%20Report.pdf. Accessed June 5, 2014
36. Wipp N. Changes to nursing home health care under the Affordable Care Act. *Spinal Column*. Published online January 29, 2014. Available at: www.spinalcolumnonline.com/news/2014-01-29/News/Changes_to_Nursing_Home_Health_Care_Under_the_Affo.html. Accessed June 5, 2014
37. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200