ABSTRACT. Children and youth with cerebral palsy present pediatricians with complex diagnostic and therapeutic challenges. In most instances, care also requires communication and comanagement with pediatric subspecialists and pediatric surgical specialists, therapists, and community developmental and educational teams. The importance of family resilience to the patient’s well-being broadens the ecologic scope of care, which highlights the value of a primary care medical home from which care is initiated, coordinated, and monitored and with which families can form a reliable alliance for information, support, and advocacy from the time of diagnosis through the transition to adulthood. This report reviews the aspects of care specific to cerebral palsy that a medical home should provide beyond the routine health maintenance, preventive care, and anticipatory guidance needed by all children. Pediatrics 2004;114:1106–1113; cerebral palsy, developmental disability, medical home, chronic illness, spasticity.

INTRODUCTION

Cerebral palsy is the third most common major developmental disability, after autism and mental retardation. More than 100 000 Americans younger than 18 years are affected by cerebral palsy, and the 30-year survival rate is nearly 90%,1,2 The diversity of individuals with cerebral palsy together with the range of severity and complications makes this condition a challenge for health care systems. Diagnosis may be delayed, care may be fragmented, routine preventive care may be overlooked, and transition to adult health care services may be haphazard at best. In addition to the effects on individuals and families, each new case of cerebral palsy involves an average lifetime cost of $503 000.3 As such, the primary care management of cerebral palsy provides an opportunity to implement the medical home model4 and improve the overall quality of care of affected individuals and their families.

BACKGROUND

Cerebral palsy is a heterogeneous group of neuromotor conditions involving disordered movement or posture and weakness resulting from a nonprogres-

sive brain lesion, injury, or malformation occurring prenatally or in the first 2 years of life. In 1843, William Little, MD, pioneered early efforts to classify subtypes of cerebral palsy, which was once called Little’s disease.5 Sigmund Freud, MD, expanded narrow assumptions that cerebral palsy resulted from birth trauma and anoxia by suggesting the possibility of predisposing factors and counseled against classification by causes until evidence for causation was clearly established; this is a challenge that continues today.6

Cerebral palsy may be defined further by its topography (quadriplegia, hemiplegia, diplegia) or by its pathophysiology (pyramidal or extrapyramidal). Pyramidal lesions result in predominantly spastic types of cerebral palsy, and extrapyramidal insults cause dyskinetic types including hypotonic, choreoathetoid, and atactic cerebral palsy. Overlapping or mixed forms of cerebral palsy are common. The overall prevalence of cerebral palsy is between 1.5 and 2.0 cases per 1000 live births and has increased slightly since 1970.7 However, surviving premature infants with birth weight less than 1500 g experience a risk of cerebral palsy of 90 per 1000 live births, and 50% of new cases of cerebral palsy occur in infants weighing less than 1000 g at birth.3

Although the diagnosis of cerebral palsy refers only to the presence of a nonprogressive motor impairment, children with cerebral palsy experience a range of comorbid conditions including mental retardation, sensory impairment, and seizures. They are subject to orthopedic and other functional complications of their primary neuromotor disorder, such as limitations of movement, scoliosis, joint instability, bowel and bladder dysfunction, dysarthria and dysphagia, and altered growth and nutrition. The physical and psychological consequences of compromised mobility and independence, difficulties with communication, altered appearance, and chronic illness may also require identification and intervention.

ETIOLOGY AND RISK

Cerebral palsy may result from a wide range of causes including congenital, genetic, inflammatory, anoxic, traumatic, toxic, and metabolic. Only 6% or 7% of cases result from asphyxia at birth, and as many as 80% seem to be prenatal in origin.8 Preterm birth is the most common antecedent event, but cau-
sality and coincidence are not always clearly dis-

guished. Although significant postnatal intraventric-

ular hemorrhage is likely to have neurologic 

sequelae, most hypoxic-ischemic injuries associated 

with cerebral palsy are prenatal.\textsuperscript{3,9,10} The cause of 

prenatal brain injury usually eludes identification, 

but recent studies have suggested that prenatal ma-

ternal chorioamnionitis may play a significant role, 

accounting for as many as 12\% of cases of spastic 

cerebral palsy in term infants and more than twice 

that among preterm infants.\textsuperscript{11} Nevertheless, a 

specific cause for cerebral palsy often cannot be deter-

mined, and an interplay of multiple factors is likely 

in many instances.

A variety of risk factors has been associated with 

cerebral palsy. Perinatal events such as preterm 

birth, low birth weight, asphyxia, intracranial 

hemorrhage, infection, seizures, hypoglycemia, and hy-

perbilirubinemia would warrant careful develop-

mental and neurologic screening during subsequent 

primary care office visits. Prenatal risk factors are 

more nonspecific and harder to identify but include 

intrauterine infections, teratogenic exposures, pla-

cental complications, multiple births, and maternal 

conditions such as mental retardation, seizures, or 

hyperthyroidism. Socioeconomic factors may in-

crease risk but also may be linked to other patho-

physiologic factors such as low birth weight or pre-

term birth.

**DIAGNOSIS AND INITIAL COUNSELING OF 

FAMILIES**

The diagnosis of cerebral palsy is a clinical deter-

mination made through neurologic and develop-

mental surveillance and an awareness of risk factors. 

Early brain development results in a gradual and 

variable pattern of emergence of signs of cerebral 

palsy, complicating the diagnosis. Spasticity may be 

preceded by hypotonia, which, although associated 

with delayed motor milestones, may be less obvious 

to parents and clinicians. On the other hand, early 

alterations in movement and tone may subsequently 

attenuate or disappear. Efforts to standardize or for-

malize such observations are helpful in infants at 

high risk or those who have suspicious findings from 

developmental screening during well-child care. 

Clues during well-child visits include the persistence 

of infantile reflexes, delayed appearance of postural 

and protective reflexes, asymmetrical movements or 

reflexes, variations in muscle tone, and delays in the 

emergence of motor milestones.\textsuperscript{12} Primary care phy-

sicians can enhance their assessment through the use 

of a more rigorous neuromotor examination such as 

that of Milani-Comparetti and Gidoni.\textsuperscript{13} Standard-

ized instruments such as the Bayley Scales of Infant 

Development, Bayley Infant Neurodevelopmental 

Screener, or the Movement Assessment of Infants 

provide scores that may be predictive of long-term 

motor impairment.\textsuperscript{14}

The consideration of specific underlying causes of 

motor delays and impairments found on neurologic 

examination may be important. Conditions for which 

an intervention might prove crucial, such as a treat-

able metabolic disorder or child abuse ("shaken-baby 

syndrome"), must not be overlooked. Other identifi-

able syndromes and conditions may have prognostic 

significance or associated complications or recur-

rence risks. A dysmorphology or genetics consulta-

tion may be useful to rule out specific conditions in 

which cerebral palsy is one of the characteristics. 

Brain imaging, usually by magnetic resonance imag-

ing, may be performed to identify such causes as 

intracranial hemorrhage/infarction or cerebral dys-

genesis.\textsuperscript{12}

When the primary care physician becomes suspi-

cious of cerebral palsy, it is important to share those 

concerns with parents. Parents may understand and 

cope better with the eventual diagnosis of cerebral 

palsy if they feel involved in the diagnostic process 

from the beginning. Furthermore, the symptoms and 

signs themselves, before they are sufficient for a di-

agnosis, may already be worrisome to parents and 

will usually justify a referral for early-intervention 

services. The motor delays alone may also confer 

eligibility for Supplemental Security Income, which 

in turn may (in most states) provide Medicaid eligi-

bility.

The average child with cerebral palsy is not diag-

osed until approximately 12 months of age,\textsuperscript{3,15} and 

some experts have suggested that a definitive diag-

nosis should be deferred until 2 years of age.\textsuperscript{3} When 

it becomes clear that a fixed pattern of altered move-

ment, muscle tone, and reflexes is associated with 

weakness and delayed motor milestones, then a di-

agnosis of cerebral palsy is warranted. As with other 

developmental disabilities, care should be taken in 

the process of informing parents. The diagnosis 

might be framed in provisional terms for a mildly 

affected child younger than 2 years because of the 

possibility of improvement. The term “cerebral pal-

sy” must be presented and discussed carefully 

with parents to avoid misunderstanding of its mean-

ing and range of implications. The prognosis is un-

 certain in nearly all children at the time of diagnosis, 

particularly with respect to specific outcomes such as 

independent ambulation, language, or cognitive abil-

ity. Children with the most severe motor involve-

ment (not rolling over or persistent infantile reflexes 

at 12 months of age or not sitting by 24 months of 

age) are less likely to be independent walkers, al-

though this may vary with the type of cerebral pal-

sy.\textsuperscript{16} The Gross Motor Function Classification System 

provides a valid tool for the classification of severity 

of cerebral palsy and prognostication about motor 

skills.\textsuperscript{17}

Plans need to be made with the family for a defin-

itive diagnostic evaluation.\textsuperscript{12} Most children and fam-

ilies will benefit from referral to a multidisciplinary 

neuromotor clinic or team when available. This team 

may include a pediatric orthopedist, pediatric physi-

atrist, developmental pediatrician, pediatric neuro-

logist, pediatric neurosurgeon, nurse coordinator 

and/or social worker, pediatric physical therapist, 

and orthotist. Other therapeutic clinicians such as 

psychologists, occupational and speech therapists, 

therapeutic recreation specialists, dietitians or nutri-

tionists, and assistive technology technicians may 

also be members of such teams.
Managing Spasticity

Seventy-five percent of children with cerebral palsy have spasticity. Active and careful management of spasticity is important to decrease or prevent deformity, promote function, alleviate pain, and increase the ease of caregiving. A plan for spasticity management may integrate physical therapy, orthopedic and orthotic management, and systemically or regionally administered medication. Most patients require daily range-of-motion exercises with regular monitoring and supervision by a physical therapist. These exercises should be supplemented by periodic pediatric orthopedic, pediatric neurosurgical, and/or psychiatric consultation for the consideration and implementation of more specialized interventions. The unopposed, deforming forces of increased muscle tone may be altered by casting and orthotic devices or by soft-tissue or bony surgery. Furthermore, osteoporosis may result from diminished weight-bearing, compromised nutritional status, and use of some anticonvulsants and may lead to pathologic fractures.

Direct treatments of spasticity involve a progressive and proactive approach moving from less invasive to more invasive modalities. Traditional therapeutic and orthotic management may be supplemented with oral medication if spasticity is generalized. Benzodiazepines, including diazepam, clonazepam, and clorazepate dipotassium, provide general relaxation and antispasticity effects, but use may be limited by sedation. These drugs demonstrate a benefit for athetosis as well as spasticity and may have enhanced benefit in combination with other drugs such as dantrolene sodium.

Baclofen is most effective for spasticity associated with spinal cord lesions but equals diazepam in improving tone and movement in cerebral palsy with somewhat less sedation. Baclofen and benzodiazepines act centrally on synaptic neurotransmission, and dantrolene directly affects muscle contractility and has proven useful in treating the spasticity of cerebral palsy. Hepatotoxicity is a serious issue with long-term use of dantrolene in 1% of cases, and adverse effects include excessive weakness and gastrointestinal distress. The α2-agonist tizanidine hydrochloride may induce less reduction in strength than baclofen and diazepam but may cause more sedation. Dry mouth and hypotension also may occur with tizanidine.

If oral medications prove insufficient or if spasticity is focal, more invasive methods including specific nerve and motor blocks and botulinum-toxin injections can be considered. The latter are useful for the treatment of focal spasticity in a specific muscle group. A single set of injections will produce clinical results in 1 to 3 days, peak after 4 weeks, and provide benefit for 3 or 4 months with rare adverse effects. Injections may be repeated every 3 to 6 months, sometimes delaying or obviating the need for surgery.

By using a pump placed in the lower abdomen and an intrathecal catheter, baclofen can be delivered continuously into the intrathecal space. This technique decreases systemic adverse effects and the dose of baclofen required, thereby increasing the efficacy for a subgroup of significantly involved children with cerebral palsy. For appropriate candidates with severe spasticity, a baclofen pump may increase functionality or improve the quality of caregiving and may be particularly useful in the treatment of dystonia when oral medication has failed or resulted in unacceptable adverse effects. However, intrathecal baclofen may be associated with complications and adverse effects including drug-related (hypotonia, weakness, nausea, vomiting, alteration in bowel and bladder function) and device-related (seroma, infection, catheter problems) complications. The most serious complication may result from overinfusion, usually related to programming errors, which may cause respiratory suppression and reversible coma. With both oral and intrathecal baclofen, rapid withdrawal should be avoided.

Dorsal rhizotomy is a surgical approach to spasticity aimed at decreasing the stimulatory afferent input from spastic muscles by severing lumbosacral dorsal rootlets. The greatest benefit is seen in young children (3-7 years of age) with spastic diplegia but stable trunk control and good lower extremity strength.

Associated Care Issues

Cerebral palsy imposes an extraordinary metabolic burden associated with spasticity and disordered movement. Increased fluid and caloric needs may be compromised further by problems with the mechanics of chewing and swallowing and with gastroesophageal reflux. Nearly half of all children with cerebral palsy have evidence of significant undernutrition. Particular attention should be given to ensuring adequate calcium and vitamin D intake. The recognition and early treatment of undernutrition may require skilled nutritional and dietary assessor.
ment, the involvement of a feeding or dysphagia team, and consultation with a pediatric gastroenterologist for assistance in the treatment of reflux or decision-making about gastrostomy tube feeding. Excessive weight gain, particularly associated with gastrostomy tube feeding, must also be avoided because of its effects on health, mobility, caregiving, and adaptive equipment.

Altered smooth muscle and sphincter tone together with the effects of medications, diminished activity, and variable hydration contribute to the high incidence of constipation in children with cerebral palsy. Many individuals with cerebral palsy require regular interventions including oral stool softeners and bowel stimulants, rectal suppositories, and occasionally enemas. For children for whom constipation is a recurring problem, a regular program should be followed. Pediatric gastroenterologic consultation may be helpful in some cases. Children with cerebral palsy experience a greater likelihood of neurogenic bladder dysfunction complicating the achievement of independence with toileting and increasing the risk of urinary tract complications. Pediatric urologic consultation and appropriate studies of bladder function may be required.

Dental care may require special attention to the consequences of altered oral motor tone, enamel dysplasia, bruxism, tongue movements, mouth breathing, anticonvulsant medications, and challenges to dental hygiene maintenance. Drooling is a problem for approximately 10% of children with cerebral palsy and presents health and cosmetic issues. Interventions may include oral motor stimulation therapy, behavioral modification, stylish scarves, medications (eg, glycopyrrolate), botulinum-toxin injections, oral appliances, or surgery.

Pain can be a challenge to assess in an individual with cerebral palsy, particularly if there is significant impairment of communication skills, cognitive functioning, or both. Pain may be suspected when there is a persistent change in mood, temperament, appetite, sleep behavior, or tolerance of movement. Evaluation may require a thoughtful but systematic review of potential causes including dental pain, gastroesophageal reflux, constipation, orthopedic pain, and urinary tract problems, including kidney stones.

Brain injury or dysgenesis resulting in cerebral palsy also may affect higher cognitive functioning, resulting in evidence of learning disability, language and communication impairment, autism, and, in approximately 50% of cases, mental retardation. Appropriate neuropsychological and psychoeducational assessments may facilitate a better understanding of learning style and more appropriate educational programming and future planning.

As with many chronic conditions associated with constant and variable manifestations, complementary and alternative methods of treatment for cerebral palsy are common. Many of these interventions are promoted by enthusiastic advocates but have little more than testimonial evidence of efficacy. Some, such as “hippotherapy” (therapeutic horseback riding), have few risks and intuitively logical benefits in terms of self-esteem and confidence building as well as possible improvements in balance, tone, and range of motion. On the other hand, hyperbaric oxygen therapy, advocated as a method of reviving injured brain tissue, has far more cost and risk in the face of no evidence of improvement in function. Nutritional supplements have been promoted for many developmental disabilities including Down syndrome, autism, and cerebral palsy, but beyond what is needed to maintain normal nutrition, there is no scientific evidence of benefit. Variations on methods of motor treatment associated with the “patterning” technique continue to be offered to families with no evidence of usefulness despite a high cost and time commitment for families. The primary care medical home can partner with families in their exploration of therapeutic alternatives by assisting in the collection of information, offering review of scientific claims and evidence, and maintaining a supportive, nonjudgmental approach.

Care Over the Long-Term

All office visits for children with cerebral palsy should be anticipated as requiring extra time and scheduled as such. The regular schedule of visits for well-child care and anticipatory guidance will require supplementation with additional periodic chronic condition management visits. It is the responsibility of the medical home to ensure that routine preventive care goals are met and additional preventive care requirements associated with cerebral palsy are fulfilled in a timely way. A written care plan should be developed together with the child and family and reviewed at each office encounter. Care planning for children with particularly complex medical issues may include an emergency information form for use when care is provided in an emergency department or by health care professionals who are less familiar with the child and family (available at www.medicalhomeinfo.org/tools/assess.html). Physical access to the office, examination rooms, and toilets should be evaluated starting from the parking lot for a typical office visit. Inviting a child in a wheelchair or with other assistive equipment on a “ride or walk-through” of the office will highlight obstacles and supplement the regulatory provisions of the Americans With Disabilities Act (Pub L No. 101–336 [1990]). The periodic solicitation of parental and patient input about ways in which medical-home office systems could be changed to improve the care experience can be obtained through mini-surveys, focus groups, or suggestion boxes.

A complete review of the coding and reimbursement options in the provision of a medical home for a child with cerebral palsy is beyond the scope of this report. Chronic condition management may be provided as an extension of a preventive medicine visit by adding the -25 modifier to a separately reported office or other outpatient services code. In this instance, the procedures involved with the preventive medicine visit and those involved in follow-up of cerebral palsy need to be documented clearly and separately in the medical record. Alternatively, chronic condition management visits may be scheduled separately from preventive-medicine visits and
reported as time-related office or other outpatient visits from among the series of codes from 99212 to 99215. The medical record must provide appropriate documentation of the time involved for the visit, including a statement that more than half of the visit was devoted to counseling and discussion of issues related to the child’s diagnosis. Team conferences or “wrap-around” meetings with early intervention or school staff or with an interdisciplinary team for planning or coordination do not need to include the child and can be coded as 99361 or 99362 for 30 and 60 minutes, respectively. For children receiving home health services or those in skilled nursing settings, care plan oversight time can be coded and billed as 99374 and 99375 for less than or more than 30 minutes, respectively. When services are prolonged beyond the time frames provided by the original code, there are a number of “prolonged physician services” codes to account for the extra time involved with or without direct patient contact (codes range from 99354 to 99359). Some medical-home settings are experimenting with drop-in group medical appointments (“DIGMA” visits), in which several children with cerebral palsy and their parents or guardians are seen simultaneously for the purpose of parent education on topics related to cerebral palsy, entitlements and benefits, patient and parent education, and family support. The 99078 code can be used for these physician educational services rendered in group settings. Unfortunately, the latter code as well as a number of others relevant to medical home services for children with cerebral palsy may frequently be denied by public, and especially private, payers. Medical home staff members should be aware of the codes covered by individual payers and consider advocating with individual health plans for coverage of codes such as those described above.

SUPPORTING CHILDREN, YOUTH, AND FAMILIES

Although there have been controversies about the effects of specific therapies on the achievement of specific developmental outcomes for children with cerebral palsy, there is little doubt that the prevention of orthopedic complications, the achievement of alternative means of communication, the optimization of motor skills, and the close monitoring of nutrition and growth have positive effects on the well-being and realization of potential in most children with cerebral palsy. In addition, early responses to family-support needs may enhance resilience and coping and equip families with some of the “marathon skills” that caring for their child may require.43 With this in mind, prompt referral to an early-intervention professional is important for children from birth to 3 years of age.44 The diagnosis of cerebral palsy need not be confirmed; suspicion of motor delays or altered tone and movement are sufficient to justify such a referral. After 3 years of age, the child with cerebral palsy is likely to be eligible for special-education services from the local educational agency serving the child’s neighborhood or community.45

Among the most important roles for the medical home are being aware of the broad array of family needs and facilitating the family’s access to support.46 Many parents will benefit from parent-to-parent contact with a more experienced family as a source of information, perspective, and self-esteem. The daily demands of home care may gradually exhaust families, and child care may not be available from conventional community providers. Parents can be encouraged to use respite care to offset the fatigue of ongoing care. The medical home should be prepared to provide advocacy for public and private educational and financial entitlements including participation in the development of individualized education programs (formerly called individual education plans) or Section 504 plans in school settings.45 Many health insurance plans do not have benefit packages that favor children with chronic conditions, and thus letters of medical necessity, contacts with health plan medical directors, and other forms of advocacy may be necessary. The medical home is ideally positioned to monitor the needs of siblings at times when children with cerebral palsy demand and receive much of the parents’ energy and attention. In addition to their own routine health needs, siblings may have milder challenges that do not receive sufficient attention or more specific fears and conflicts about their chronically affected brother or sister. Finally, a family’s cultural heritage can affect the style and content of their support for their child with cerebral palsy because of language or educational barriers or because of less obvious cultural differences in beliefs about a condition such as cerebral palsy.47 A culturally effective medical home will recognize these barriers, anticipate their possible implications, and actively attempt to ameliorate their consequences.

Cerebral palsy poses life-long challenges for those affected, and more than 90% of individuals with cerebral palsy survive to adulthood. It is important that the pediatric primary care medical home opens an early dialogue with families about planning for the transition to adulthood.46,49 Financial and estate planning may be important to begin in very early childhood, and educational, vocational, and guardianship planning should begin in early adolescence. The medical home will need to devote specific time and attention to transitions to adult health care including primary and specialty care. The pediatrician can provide specific longitudinal knowledge about an individual child as well as a current care plan, characterizing recent issues and plans for addressing them to the adult primary care setting.

OUTCOMES AND QUALITY OF LIFE FOR INDIVIDUALS WITH CEREBRAL PALSY

Using the World Health Organization and National Center for Medical Rehabilitation Research models, the severity of cerebral palsy can be assessed at the cellular (pathophysiology), organ (impairment), or whole-person (disability) level.50–52 However, according to the National Center for Medical Rehabilitation Research model, quality of life for individuals with cerebral palsy cannot be determined simply by measures at any of these levels. Instead, quality of life depends on a complex interplay be-
tween the individual’s functional limitations, the family’s assets and challenges, and the resources and limitations of the society in which the individual and his or her family are immersed. Just as simply surviving the pathophysiologic events causing cerebral palsy does not ensure a high quality of life, the presence of severe organic impairment does not predict a uniformly dismal outcome.

Most children with cerebral palsy live at home with their families, attend regular classrooms at their neighborhood schools, and participate in a variety of natural community activities. As adults, most continue to live in community settings, but one third live at home with their parents, whose ability to continue caregiving may decrease as they age. Twenty percent of adults with cerebral palsy are ambulatory, and 40% can walk with assistance; the remaining 40% are nonambulatory.

The horizon of opportunity for individuals with cerebral palsy has continued to expand with improvements in health care, developmental and educational services, and support for individuals and families in community settings. The primary care medical home is an organizing force for the provision of appropriate preventive health care and for the integration of care into the fabric of other important supports and services.

IMPORTANT POINTS FOR THE PEDIATRICIAN

1. Be aware of risk factors associated with cerebral palsy and incorporate neuromotor screening into routine developmental surveillance.
2. Provide prompt referral for early-intervention services for all children with alterations in motor development without waiting for diagnostic confirmation of cerebral palsy.
3. Partner with parents in the pursuit of a diagnosis and a culturally effective discussion of its implications for health, development, and family life.
4. Include screening for sensory impairments in the care plan for all newly identified children with cerebral palsy; brain imaging should be performed when appropriate.
5. Consider referral to a geneticist or pediatric neurologist in the presence of dysmorphic features, positive family history, or any atypical clinical characteristics.
6. Make your office a medical home that includes services such as care coordination, a written care plan, patient and family education, parent-to-parent referral, and advocacy.
7. After the definitive diagnosis of cerebral palsy, begin comanagement with a multidisciplinary neuromotor team and schedule regular chronic condition management visits in addition to regular preventive medical care.
8. Manage spasticity by using a “ladder” approach, starting with the least invasive interventions and adding treatments as needed.
9. Maintain vigilance for the new onset of comorbid conditions such as seizures, cognitive or learning disabilities, nutritional complications, etc.
10. Advocate with parents to school personnel about appropriate educational and therapeutic strategies including: physical, occupational, and speech therapy; nursing; and adaptive and assistive technology.

11. Be aware of and make timely referrals to community and state agencies providing support and services to which the child and family may be entitled.
12. Be a sensitive and useful resource for families in their exploration of complementary and alternative interventions for cerebral palsy.
13. Solicit feedback from families of children with cerebral palsy about the care and services provided in your office and how they could be improved.
14. Assess the quality of your medical home services for children with cerebral palsy and engage in systematic, incremental efforts to improve them.
15. Begin planning for the transition to adulthood with the child and family as early as possible but no later than 12 years of age.

Committee on Children With Disabilities, 2003–2004

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RESOURCES FOR THE MEDICAL HOME

American Academy of Pediatrics. Coding and reimbursement. AAP coding hot line and fax-back service: 1-800-433-9016, extension 4022

American Academy of Pediatrics. Coding for Pediatrics (available annually from the American Academy of Pediatrics: provides easy reference to pediatric codes including clinical examples for children with special health care needs)

American Academy of Pediatrics, National Center of Medical Home Initiatives for Children With Special Needs (information and tools for developing and providing a medical home for children with special health care needs).

Available at: www.medicalhomeinfo.org

Center for Medical Home Improvement. Available at: www.medicalhomeimprovement.org

Family Voices. Available at: www.familyvoices.org


Kids as Self Advocates. Available at: www.fvkasa.org

United Cerebral Palsy. Available at: www.ucp.org

ADDITIONAL RELEVANT AMERICAN ACADEMY OF PEDIATRICS POLICY STATEMENTS/CLINICAL REPORTS


American Academy of Pediatrics, Committee on Children With Disabilities. The role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. *Pediatrics*. 2000;106:854–856


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.
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The online version of this article, along with updated information and services, is located on the World Wide Web at:

/content/114/4/1106.full.html