

## CLINICAL REPORT

Guidance for the Clinician in Rendering Pediatric Care

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### Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy

**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%.<sup>1,2</sup> 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.<sup>3</sup> As such, the primary care management of cerebral palsy provides an opportunity to implement the medical-home model<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup>

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, choreo-athetoid, and ataxic 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.<sup>7</sup> 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.<sup>3</sup>

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.<sup>8</sup> Preterm birth is the most common antecedent event, but cau-

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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sality and coincidence are not always clearly distinguished. Although significant postnatal intraventricular hemorrhage is likely to have neurologic sequelae, most hypoxic-ischemic injuries associated with cerebral palsy are prenatal.<sup>3,9,10</sup> The cause of prenatal brain injury usually eludes identification, but recent studies have suggested that prenatal maternal 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.<sup>11</sup> Nevertheless, a specific cause for cerebral palsy often cannot be determined, 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 hyperbilirubinemia would warrant careful developmental 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, placental complications, multiple births, and maternal conditions such as mental retardation, seizures, or hyperthyroidism. Socioeconomic factors may increase risk but also may be linked to other pathophysiologic factors such as low birth weight or preterm birth.

#### DIAGNOSIS AND INITIAL COUNSELING OF FAMILIES

The diagnosis of cerebral palsy is a clinical determination made through neurologic and developmental 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 formalize 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.<sup>12</sup> Primary care physicians can enhance their assessment through the use of a more rigorous neuromotor examination such as that of Milani-Comparetti and Gidoni.<sup>13</sup> Standardized 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.<sup>14</sup>

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 treatable metabolic disorder or child abuse ("shaken-baby

syndrome"), must not be overlooked. Other identifiable syndromes and conditions may have prognostic significance or associated complications or recurrence risks. A dysmorphology or genetics consultation may be useful to rule out specific conditions in which cerebral palsy is one of the characteristics. Brain imaging, usually by magnetic resonance imaging, may be performed to identify such causes as intracranial hemorrhage/infarction or cerebral dysgenesis.<sup>12</sup>

When the primary care physician becomes suspicious 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 diagnosis, 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 eligibility.

The average child with cerebral palsy is not diagnosed until approximately 12 months of age,<sup>3,15</sup> and some experts have suggested that a definitive diagnosis should be deferred until 2 years of age.<sup>3</sup> When it becomes clear that a fixed pattern of altered movement, muscle tone, and reflexes is associated with weakness and delayed motor milestones, then a diagnosis 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 palsy" must be presented and discussed carefully with parents to avoid misunderstanding of its meaning and range of implications. The prognosis is uncertain in nearly all children at the time of diagnosis, particularly with respect to specific outcomes such as independent ambulation, language, or cognitive ability. Children with the most severe motor involvement (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, although this may vary with the type of cerebral palsy.<sup>16</sup> The Gross Motor Function Classification System provides a valid tool for the classification of severity of cerebral palsy and prognostication about motor skills.<sup>17</sup>

Plans need to be made with the family for a definitive diagnostic evaluation.<sup>12</sup> Most children and families will benefit from referral to a multidisciplinary neuromotor clinic or team when available. This team may include a pediatric orthopedist, pediatric physiatrist, developmental pediatrician, pediatric neurologist, 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 nutritionists, and assistive technology technicians may also be members of such teams.

## ONGOING CARE IN THE MEDICAL HOME

High-quality care for most children with cerebral palsy is exemplified by the primary care medical home working in collaboration with parents, medical specialists, and community agencies.<sup>4</sup> The primary care medical home should provide proactive care coordination, including monitoring, interpreting, and orchestrating comanagement with specialists and specialty teams while communicating from the health care perspective with therapeutic, educational, family-support, and other resources in the community. The medical home also provides advocacy with payers and providers such as local school districts.

Associated factors and complications of cerebral palsy require initial assessment and ongoing vigilance. Hearing and vision may be vulnerable to the same insults that caused the neuromotor impairment. As a result, all children suspected of having cerebral palsy should undergo audiologic and pediatric ophthalmologic consultation. Seizures occur in more than 25% of individuals with cerebral palsy, with the greatest risk among those with spastic quadriplegia and hemiplegia.<sup>18,19</sup>

### Managing Spasticity

Seventy-five percent of children with cerebral palsy have spasticity.<sup>20</sup> Active and careful management of spasticity is important to decrease or prevent deformity, promote function, alleviate pain, and increase the ease of caregiving.<sup>19</sup> 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.<sup>21</sup> These exercises should be supplemented by periodic pediatric orthopedic, pediatric neurosurgical, and/or physiatric 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.<sup>22</sup>

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.<sup>23</sup> 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.<sup>23,24</sup> Baclofen and benzodi-

azepines act centrally on synaptic neurotransmission, and dantrolene directly affects muscle contractility and has proven useful in treating the spasticity of cerebral palsy.<sup>25</sup> Hepatotoxicity is a serious issue with long-term use of dantrolene in 1% of cases, and adverse effects include excessive weakness and gastrointestinal distress.<sup>26</sup> The  $\alpha_2$ -agonist tizanidine hydrochloride may induce less reduction in strength than baclofen and diazepam but may cause more sedation.<sup>27</sup> 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.<sup>26</sup> The latter are useful for the treatment of focal spasticity in a specific muscle group.<sup>28</sup> 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.<sup>29</sup> 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.<sup>30,31</sup> 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.<sup>32,33</sup> 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.<sup>34</sup> 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 assess-

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.<sup>35</sup> 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.<sup>36</sup> 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.<sup>37</sup> 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.<sup>38</sup> 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.<sup>39</sup>

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.<sup>19</sup> 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 build-

ing as well as possible improvements in balance, tone, and range of motion.<sup>40</sup> 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.<sup>41</sup> 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.<sup>42</sup> 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](http://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.<sup>43</sup> With this in mind, prompt referral to an early-intervention professional is important for children from birth to 3 years of age.<sup>44</sup> 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.<sup>45</sup>

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.<sup>46</sup> 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.<sup>45</sup> 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.<sup>47</sup> 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.<sup>48,49</sup> 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.<sup>50-52</sup> 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 strate-

gies including: physical, occupational, and speech therapy; nursing; and adaptive and assistive technology.<sup>44,45,53-55</sup>

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.

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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](http://www.medicalhomeinfo.org)
- Center for Medical Home Improvement. Available at: [www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)
- Family Voices. Available at: [www.familyvoices.org](http://www.familyvoices.org)
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- Kids as Self Advocates. Available at: [www.fvksa.org](http://www.fvksa.org)
- United Cerebral Palsy. Available at: [www.ucp.org](http://www.ucp.org)

## ADDITIONAL RELEVANT AMERICAN ACADEMY OF PEDIATRICS POLICY STATEMENTS/CLINICAL REPORTS

- American Academy of Pediatrics, Committee on Children With Disabilities. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110:1304-1306

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