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Diagnosis/symptom

Cerebral Palsy

Description:

Cerebral palsy¹ is a group of movement and posture disorders resulting from a non-progressive injury to the developing central nervous system. The causes may be prenatal (including genetic), perinatal, or postnatal. Cerebral palsy exhibits an evolving clinical picture over time as the central nervous system matures, so clinical change should be expected.

In all but the mildest cases, the diagnosis of cerebral palsy can be made by 12-18 months of age. Diagnosis is essentially clinical and is dependent on an understanding of normal motor development and its variations

The clinical evaluation of children with cerebral palsy must be ongoing. The changing appearance of cerebral palsy over time needs to be distinguished from progressive neurologic conditions including metabolic, neoplastic, or degenerative disorders.

When to initiate referral:

- Evaluation of or confirmation of cerebral palsy
- Ongoing management of issues specific to cerebral palsy and its associated conditions or secondary disability including:
 - Mobility/lower extremity function. (Most often an issue for GMFCS² classes I-III.)
 - Feeding and nutrition
 - Communication.
 - Bowel/bladder function
 - Upper extremity function

- Comprehensive recommendations for multiple issues related to severe disability. (GMFCS² classes IV-V.)

The multi-faceted nature of cerebral palsy benefits from a comprehensive, individualized approach.

The goal of every intervention is to enable each child to grow up within a family and community; to achieve his/her optimal independence in adult life, to insure comfort and ease of care, and to prevent secondary disabilities.

What can referring provider send?

- Identify specific concerns of the physician and family. This will help determine which providers will need to see the child.
- Identify age of child
- List current interventions, therapies, and treatments, including medication. Operative reports are also helpful.
- Describe functional limitations and include information about child's current activities, including recent PT/OT reports and GMFCS Classification² if used. Indicate whether child is using any assistive devices such as braces, walker, or wheelchair.
- Provide all relevant reports and evaluations including growth charts and head circumference measurements to help with nutritional assessments.
- Provide brain images,³ such as MRI, CT, or ultrasound, which are helpful in diagnosis and treatment planning.
- Particularly for mobility or musculoskeletal issues, provide existing x-rays of the spine and lower extremities.³

> Additional information:

- 1 For additional information about cerebral palsy, including further description, developmental guidelines for critical elements of care, functional assessment worksheets, and resources for professionals and families, download a copy of "Cerebral Palsy: Critical Elements of Care" from http://www.cshcn.org/forms/CP_2nd_ed_6-02.pdf.
- 2 **GMFCS:** Gross Motor Function Classification System for cerebral palsy. This tool, developed by the faculty at McMaster University and the CanChild Centre for Childhood Disability Research, is used to rate the severity of spasticity based on a functional assessment. The GMFCS is an excellent tool to communicate more clearly about the level of severity of mobility problems experienced by children with cerebral palsy. The GMFCS can be downloaded from the Centre's website at <http://www-fhs.mcmaster.ca/canchild>.
- 3 Actual images are more helpful than the reports. The center where imaging was done may be able to send a CD (DICOM compatible format) of the images. Alternatively, families can be asked to pick up the films and/or bring them to the consultation.



Diagnosis/symptom

Developmental Delay

Description:

Developmental delay is one of the most common childhood problems with an estimated prevalence of 10%. It is a descriptive rather than a diagnostic term.

Delays exist when a child does not reach specific milestones at the expected age in any area of development. Because of the wide variation at which children will reach a particular milestone, detection of delay can be challenging.

There are many potential etiologies for developmental delay; however, in many young children, a specific diagnosis cannot be made. Even in the absence of an etiologic explanation, early identification and intervention helps both children and their families.

When to initiate referral:

A consultation request for developmental delay implies that the child has either “failed” some method of developmental screening/surveillance or the family or the primary care provider has raised a specific concern.

What can referring provider send?

- Identify area of concern: global delay vs. delay in specific area (fine motor, gross motor, speech/language, personal, social) to help determine what providers will need to see the child.
- Provide all previous reports/evaluations/screenings for these issues (especially Birth to Three and school assessments). Prior medical records, especially from the newborn period, are also helpful.
- List of current interventions, therapies, treatments and any recent progress notes or testing from these providers.
- Identify decline or loss of skills (“regression”) to help determine urgency of the referral/visit.
- Identify age of child to help focus pre-referral strategies for the Primary Care Provider (PCP) while waiting for the appointment – it is important to utilize the educational and medical systems in parallel rather than in sequence.

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| Specific areas of development: | Data Needed: |
|--|--|
| Language concern | Hearing evaluation and/or results of a newborn hearing screening (can be initiated by the PMD in parallel to their referral to NDV) |
| Oral motor concerns (feeding problems) | Growth curves (including head circumferences) particularly to determine the need for nutrition or clinical feeding evaluations |
| Delayed motor milestones | All notes and information are helpful, especially the timing of achieved milestones and any unusual characteristics (asymmetry, movement patterns) |

Our goal is to work collaboratively with the primary care providers in support of each child’s community based “Medical Home.”



Diagnosis/symptom Developmental Delay

> Additional Resources:

- **FOR CHILDREN 0-3 YEARS OLD:** Primary Care Provider (PCP)/parent referral to early intervention services does not require a specific diagnosis. If either is concerned, they can contact *Healthy Mothers, Healthy Babies* 1-800-322-2588 to identify and refer the child to the local early intervention services agency (year round, no cost to families). Can be done in parallel to the referral to Neurodevelopmental Clinic.

Statewide resource:

Infant Toddler Early Intervention Program (Part C)
Department of Social and Health Services
12th and Franklin Streets
PO Box 45201
Olympia, WA 98504-5201
Phone: 360-902-8490
Fax: 360-902-8497
Web site: <http://www1.dshs.wa.gov/iteip/cicc1.htm>

- **FOR CHILDREN 3-5 YEARS OLD:** A PCP or parent referral to the local school district for evaluation/assessment does not require a specific diagnosis but the child can be made a "focus of concern" at their request.

Statewide resource:

EC Special Education Program Supervisor
Office of Public Instruction
PO Box 47200
Olympia, WA 98504-7200
Phone: 360-725-6080
Fax: 360-586-1631
Web site: <http://www.k12.wa.us/specialed/>

County Resources Guides

<http://cshcn.org/resources/Resourceguides.cfm>

Starting Point

<http://cshcn.org/resources/guides.cfm?intro=yes>



Diagnosis/symptom
Prenatal Counseling

Description:

The Neurodevelopmental Program provides prenatal counseling for women carrying fetuses with known central nervous system malformations or prenatal imaging abnormalities of the nervous system. We do not provide prenatal counseling for other birth defects in the absence of a nervous system malformation.

Our goal is to provide information to help pregnant women with reproductive decision making and/or preparation for the birth of an affected child. When indicated, we can arrange for consultation with other pediatric services such as genetics and neurosurgery. We refer all patients back to their primary obstetrical providers for ongoing pregnancy management.

Consults involving pregnancy decision-making or the need for likely neonatal management will be prioritized.

In some cases, consultation may be deferred until after birth.

When to initiate referral:

A fetus has a known or suspected central nervous system abnormality including:

- ventriculomegaly
- hydrocephalus
- spina bifida
- myelomeningocele
- encephalocele and anencephaly
- other neural tube defect
- Dandy-Walker malformation, Dandy-Walker “variant” (= cerebellar vermis hypoplasia)
- mega cisterna magna
- other cerebellar malformations
- holoprosencephaly
- agenesis of the corpus callosum
- lissencephaly

Please call the Prenatal Clinic at 206-987-5629, if there are questions about whether a referral would be appropriate.

What can referring provider send?

- Specific concerns of the pregnant woman
- Specific concerns of the referring physician
- Current gestational age of the fetus
- Whether pregnancy termination is being considered (if so, the visit will be scheduled within a few days)
- Sex of the fetus, if known (aids in preparation for X-linked disorders)
- All records from primary obstetrician and any consultants (perinatologist, genetic counselor, etc)
- All ultrasound, fetal MRI and laboratory reports
- List of tests that are pending
- Fetal MRI or ultrasound images on film or CD-ROM (DICOM compatible format)

Additional information:

- Consider an amniocyte karyotype for most fetuses (even if the central nervous system abnormality is isolated).
- For fetuses with ventriculomegaly or hydrocephalus, consider testing for CMV and toxoplasmosis on maternal blood or amniotic fluid.
- For fetuses with neural tube defects:

Consider amniotic fluid AFP and acetylcholinesterase if there is any doubt about an open versus closed neural tube defect.

If gestational age is less than 26 weeks, consider giving the woman information on the Management of Myelomeningocele Study MOMS (NIH-funded randomized trial of in utero repair for open neural tube defects) www.spinabifidamoms.com 1-866-ASK-MOMS (275-6667).



Diagnosis/symptom

Spasticity Management Clinic

Description:

The purpose of this clinic is to evaluate children with seriously impairing spasticity* due to cerebral palsy and other conditions to determine if specific treatments can improve their comfort, ease of care, or function.

The clinic also provides consultation related to dystonia, athetosis, or other movement disorders related to cerebral palsy or similar conditions.

A medical workup to determine the cause of the spasticity or other movement disorder should be done prior to seeking consultation through this clinic.

Current treatment modalities include:

- Botulinum toxin injections
- Continuous intrathecal baclofen delivered in an implantable pump
- Selective dorsal rhizotomy (SDR)

These treatment modalities are generally applicable for children over the age of two years.

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When to initiate referral:

Seek consultation through the Spasticity Management Clinic when:

- Spasticity that causes pain, functional impairment, or care difficulties is the predominant medical issue.
- Child is at least 2 years of age.

Seek consultation through the regular Neurodevelopmental Clinic when spasticity is part of a larger set of problems and not the predominant issue.

If there is any question as to whether spasticity is the predominant issue or if the requested evaluation is for oral medications, braces, PT/OT, orthopedic surgery, and treatments for other aspects of cerebral palsy, seek consultation through the Neurodevelopmental Clinic.

What can referring provider send?

- Medical records, including etiologic workup and operative records if surgery has been performed
- Description of functional limitations due to spasticity and information about child's current activities, including PT/OT reports and GMFCS** rating if this assessment tool was used
- Related radiological testing already completed, such as CT scans and MRI's of the head or spine and x-rays of the spine and hips

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> Additional information:

- Initial consultations in the Spasticity Management Clinic are designed to determine the appropriateness of a particular intervention (botox, pump, SDR) for a child. A separate, follow-up appointment will be scheduled to provide the recommended treatment.



Indications for Specific Spasticity Treatments:

In almost every situation, efforts to manage spasticity will begin with a trial of oral medications. Initial decisions regarding medication choice and dose can often be made in consultation with any of the Neurodevelopmental Service physicians, without a formal referral to the Spasticity Management Clinic. Oral medication may continue to have a significant role in the management of these patients in conjunction with the following specific therapies.

| Botulinum toxin injection | Baclofen pump | SDR |
|--|--|---|
| <ul style="list-style-type: none"> • Children approximately 2-8 years of age with relatively mild global spasticity or with lower extremity spasticity that causes difficulty with walking. • Children > approximately 4 years of age or who have severe spasticity in a localized area. • Rated I or II on GMFCS** if difficulty is in lower extremities. • Rated I to V on GMFCS** if difficulty is in upper extremities. • NOTE: There may be an emerging role for this treatment in some infants less than 2 years of age. Call to discuss appropriateness of referral in this case. | <ul style="list-style-type: none"> • Children approximately 3 years of age and older who are large enough to accommodate an abdominal implant. • Severe spasticity that causes pain or major positioning or care problems. • Children with spasticity that is greater in lower extremities or who have a combination of other movement disorders and spasticity. • Rated Level IV or V on GMFCS.** | <ul style="list-style-type: none"> • Children approximately 2-6 years of age whose spasticity is moderately severe and who have difficulty walking. • Rated Level II or III on GMFCS.** |

> Additional information:

* Spasticity is hypertonia characterized by resistance to stretch that varies directly with the velocity of passive muscle stretch (as during range of motion) beginning with a sudden catch and accompanied by exaggerated deep tendon reflexes and often clonus. Many children with cerebral palsy will have dystonia as their primary cause of hypertonia.

** GMFCS: Gross Motor Function Classification System for Cerebral Palsy. This tool, developed by the CanChild Centre for Childhood Disability Research, is used to rate the severity of functional gross motor disability. The GMFCS can be downloaded from the Centre's Web site at: www-fhs.mcmaster.ca/canchild.

Clinic phone: 206-987-2210. To request a consult or referral, please call the Clinical Intake Nurses at 206-987-2080 or toll free at 866-987-2080. You may fax a New Appointment Request Form to 206-985-3121 or toll free at 866-985-3121. To speak with a Seattle Children's physician for an urgent phone consultation, call the Physician Operator at 206-987-7777 or toll free at 877-985-4637.

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