

# On the Uptake

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## Early Detection and Intervention Toolkit for Children with Cerebral Palsy (EDIT-CP): A National Knowledge Implementation Project

### *Principal Investigators:*

- *Annette Majnemer, Research Institute of the McGill University Health Centre*
- *Darcy Fehlings, Bloorview Research Institute*
- *Tatiana Ogourtsova, Jewish Rehabilitation Hospital*
- *Zachary Boychuck, School of Physical & Occupational Therapy, McGill University (Co-Investigator)*

### *Research Coordinators:*

- *Anna Radzioch Guerin, Research Institute of the McGill University Health Centre*
- *Lauren Switzer, Bloorview Research Institute*
- *Bisman Mangat, Bloorview Research Institute*

## Background

**Cerebral palsy** (CP) is a neurological disorder caused by a non-progressive brain injury or malformation that occurs while the child's brain is immature. It is the most common physical disability of childhood and has lifelong health impacts for the child and family.

While CP primarily affects body movement and muscle coordination, the child may also experience other problems of development (e.g., behavioral, intellectual, auditory, and visual). Every case of CP is unique, with different causes, movement patterns, and severity of impairments.

Although brain damage typically occurs before birth or soon thereafter, signs of CP become gradually apparent as motor development evolves in infancy. An early diagnosis of CP matters as the earlier institution of interventions is associated with better long-term outcomes and prevention of secondary complications. Early detection and early intervention are therefore crucial as they are the key to better outcomes for young children with CP.

Learn more: [www.childhooddisability.ca/diagnosis/cerebral-palsy/](http://www.childhooddisability.ca/diagnosis/cerebral-palsy/)

## The EDIT-CP Toolkit

**EDIT-CP** refers to the **Early Detection and Intervention Toolkit for children with CP** that is designed to support clinicians to detect CP early and quickly connect children to effective early interventions.

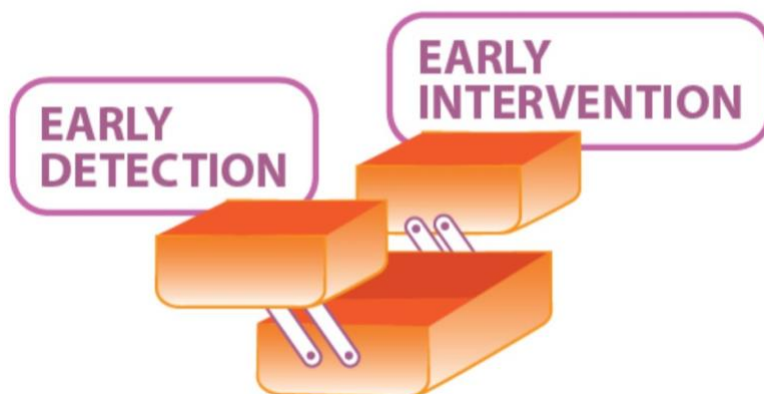
Learn more: [www.childhooddisability.ca/edit-cp-toolkit/](http://www.childhooddisability.ca/edit-cp-toolkit/)

In addition, EDIT-CP offers user-friendly information for patients and families to increase their awareness about existing approaches and help ease their way towards assessment and rehabilitation services. Timely detection of CP, along with early therapy, enable children to enhance their functional potential.

Children with CP are typically identified and followed in one of two pathways, depending on their history:

- Infants who are regularly seen at follow-up programs for children who were in neonatal intensive care units.
- Infants showing delayed or different patterns of movement are first identified and followed by a primary care provider (e.g., family physician, pediatrician).

**Early detection and intervention resources available through [EDIT-CP](#) reflect these two pathways.**



## Early Detection

***For clinicians working in follow-up programs for children who were in neonatal intensive care units and for primary care providers.***

For infants who were in neonatal intensive care units, such as those born very prematurely, there are international guidelines to [detect CP](#) early using a range of assessment tools. These tools are being used in neonatal follow-up programs that follow high-risk newborns systematically over the first years of life. One of these tools is the Hammersmith Infant Neurological Examination (HINE) (<https://hollandbloorview.ca/our-services/programs-services/neuromotor-services/hammersmith-infant-neurological-examination-hine>). The HINE is a standardized assessment that can be used to help identify high probability of CP in infants as young as two months. Using the HINE scores, clinicians can determine appropriate next steps which may include a referral for early intervention programs.

However, many children with CP were not born early and did not have a high-risk delivery, requiring neonatal intensive care. So, a different strategy is needed for early diagnosis for these children. Tools in the EDIT-CP toolkit were developed to help family doctors and pediatricians detect CP in infants as part of their well-baby care visits. The figure below is designed to assist primary care physicians (family doctors, pediatricians) in detecting CP early and referring the children as quickly as possible for diagnosis and for treatment. It provides 6 clinical features, 2 warning signs, and 5 referral recommendations.

A parent-version of this tool, as well as French translations of both versions, are being developed and will also be available for free online soon.

## Early Intervention

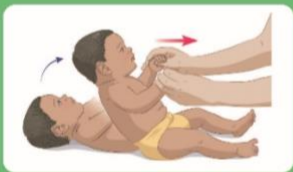
The first years of life are a critical period for brain development. For a child with CP, maladaptive brain connections often develop due to disuse of affected limbs. This can ultimately compromise motor learning and performance. At this stage of life, intensive early rehabilitation interventions can greatly augment functional outcomes and minimize secondary disabilities. Over the last two decades, a significant number of high-quality early intervention studies have been published for young children with CP. However, important gaps remain between the publication of research and moving this new evidence into clinical practice.

The [EDIT-CP](#) toolkit aims to make research evidence on early interventions for young children with CP more accessible to both therapists and families. The EDIT-CP toolkit includes information about 22 early interventions, derived from multiple clinical trials (>50% of studies are of high research quality).

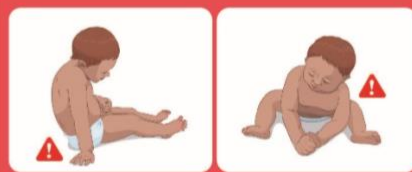
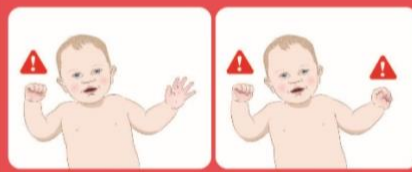
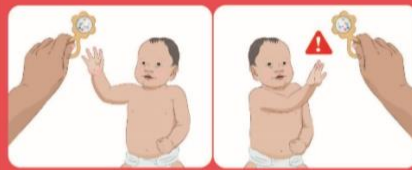
Early interventions for young children with CP are diverse. Some focus on improving arm movements and the use of both hands (e.g., constraint-induced movement therapy, CIMT), while others target to coach caregivers in how to best stimulate their child's development (e.g., COPing with and Caring for infants with special needs (COPCA) program) or improving child's chewing and feeding abilities (e.g., Oral Motor Therapy). Different rehabilitation professionals are delivering these interventions, including physical therapists, occupational therapists, and speech language pathologists. The existing early interventions are suitable for children with different types and severities of CP.

# PROMPTs for Cerebral Palsy Referral

## TYPICAL Development



## ATYPICAL Development



## CLINICAL FEATURES

If "YES" to any ONE of these ATYPICAL SIGNS, refer to a child neurologist or a developmental pediatrician for diagnostic assessment

The child consistently demonstrates a **hand preference** before 12 months of age

The child demonstrates **stiffness or tightness in the legs** between 6–12 months of age (e.g. unable to bring their toes to mouth when having their diaper/nappy changed)

The child consistently keeps their **hands fisted (closed/clenched)** after the age of 4 months

The child demonstrates a **persistent head lag** beyond 4 months of age

The child is **not able to sit without support** beyond 9 months of age

The child demonstrates **consistent asymmetry of posture and movements** after the age of 4 months

## WARNING SIGNS



If “YES” to EITHER of these signs, monitor rather than immediately refer for diagnostic assessment

Abnormal if this persists beyond 6 months:



The child demonstrates a **persistent Moro reflex** beyond 6 months of age



The child demonstrates **consistent toe-walking** or **asymmetric-walking** beyond 12 months of age

## REFERRAL RECOMMENDATIONS

When referring to a medical specialist for diagnostic assessment, also refer to:

- All children should be referred to a **motor intervention specialist** (e.g. pediatric occupational therapist and/or pediatric physical therapist)
- If the child manifests a delay in communication, they should be referred to a **speech-language pathologist**
- If the child manifests hearing concerns, a referral should be made to an **audiologist**
- If the child manifests vision difficulties (e.g. not fixating, following, and/or tracking), a referral should be made to an **optometrist** or an **ophthalmologist**, and to a **functional vision specialist** (e.g. occupational therapist with expertise in pediatric vision; early childhood vision consultants)
- If the child manifests feeding difficulties (e.g. poor sucking, swallowing, choking, not gaining weight), a referral should be made to a **feeding specialist** (e.g. occupational therapist or speech-language pathologist)



Childhood disability LINK is a bilingual website Linking Information and New Knowledge on childhood disability to service providers and families. The website also focuses on enhancing the awareness and understanding of research on a variety of issues in childhood disability.

Please visit us at:  
[www.childhooddisability.ca](http://www.childhooddisability.ca)

Learn more about the  
**EDIT-CP toolkit** at:  
[www.childhooddisability.ca/edit-cp-toolkit/](http://www.childhooddisability.ca/edit-cp-toolkit/)

## Early Intervention (continued)

Each section of the webpage offers a summary of different types of early intervention and answers typical questions that parents and clinicians may have about it. In addition, there is also information for clinicians about studied outcomes and effectiveness of the different approaches.

One such approach is called Baby Constraint Induced Movement Therapy or Baby CIMT. Baby CIMT is an evidence-based motor therapy for children under 2 years of age that is recommended as soon as babies are suspected to have hemiplegic CP or favor one hand/arm over the other. The caregivers are coached by the therapist in ways to play with their child to encourage use of the 'less used' hand. Sharing resources on Baby-CIMT for both therapists and caregivers is important in facilitating early intervention (<https://hollandbloorview.ca/services/programs-services/neuromotor-services/cimt>).

## Impact

Approximately 600 children are diagnosed with CP in Canada each year, and about half of those children are not followed closely by medical professionals. If those 300 children could be identified as having CP at an earlier age and have access to evidence-based early intervention programs, it would help counteract the maladaptive brain connections that evolve in the non-damaged regions of the brain. Furthermore, early detection has important positive impacts for families, to relieve stress, empower caregivers and promote adaptive coping. [EDIT-CP](#) supports clinicians and families in detecting CP earlier and quickly connecting children to evidence-informed early interventions, thus enhancing their developmental progress and functional potential of children, once diagnosed with CP.