

## **NINDS CDE Project Cerebral Palsy Pain Instrument Summary**

The Pain Working Group adopted the definition of chronic pain as pain lasting more than 3 months, clinically identified as (a) chronic musculoskeletal pain, such as persistent or recurrent pain that arises as part of Cerebral Palsy causing structural changes to bone(s), joint(s), muscle(s), or related soft tissue(s); (b) chronic visceral pain that frequently originates from the internal organs of the abdominal (often caused by gastro-esophageal reflux) and pelvic cavities; and (c) postsurgical and posttraumatic pain that is pain that persists beyond normal healing frequently after surgery and some types of injuries.

The Pain Working Group took the approach of standardizing chronic pain-related data collection and assessment in studies of children and young people with Cerebral Palsy by: (1) recommending a set of tools that comprehensively represent the impact of chronic pain on children's functioning; (2) identifying valid and reliable chronic pain measures to be recommended for routine use across NINDS-funded clinical studies and clinical practice; and (3) identifying measurement gaps that could be addressed in future research initiatives.

Pain measures were reviewed and included if (1) the assessment was developed specifically for chronic pain; (2) the assessment was developed for pediatric populations (children 0 to 18 years); (3) the main focus of the assessment is pain, or most questions included are about pain (i.e., more than 3 questions); (4) the assessment fits within one of the pain categories (i.e., intensity, interference, behavior, quality, or location) (e.g., beliefs about pain and fear of movement); and (5) the assessment is available in English.

Pain measures were excluded if (1) the assessment was developed specifically for a different diagnosis; (2) pain is due to an event outside of the scope of the diagnosis (i.e., trauma); (3) the main focus of the assessment is not on pain or has very limited questions about pain (i.e., 1-3 questions); (4) the assessment does not fit within one of the pain categories (i.e., intensity, interference, behavior, quality, or location); and (5) the assessment is a duplicate.

The target population of this initiative was children and youth aged 0 to 18 years with a diagnosis of Cerebral Palsy or considered to be at risk of developing Cerebral Palsy. A summary table of recommendations is included below.

The Pain Working Group identified a few areas that are unique or highlight a unique concern in chronic pain assessments for children with Cerebral Palsy. There are very few measures that are validated for use with children and adolescents who are nonverbal or have intellectual disabilities. For measures that assess physical function in relation to chronic pain in children and adolescents, pre-existing physical disabilities that impact physical function or performing of activities are not included or addressed in these measures.

In comparison to many other Cerebral Palsy standards, many of the pain measures have not been specifically validated for use in this population. Some measures selected are commonly used in research across multiple conditions such that specific validation in this population is unlikely (e.g., Visual Analog Scale). Like other Cerebral Palsy standards, we approached this task of identifying best measures to use for evaluating chronic pain in children with Cerebral Palsy in research with the framework of the

International Classification of Function, Disability, and Health (ICF). The Pain Working Group was able to identify measures covering the major categories of this framework, though some measures were included as “Exploratory”. The Pain Working Group also identified measures applicable for children of a variety of ages and abilities. Unique to the pain measures, the Pain Working Group identified the category or categories of pain that the measure assesses. In comparison to other NINDS CDE disease groups, this group of measures assembled for assessing chronic pain in children with Cerebral Palsy is one of the largest and most comprehensive group of pain measures for a disorder that is not a primary pain disorder.

There is a need for validated measures of chronic pain across the ICF framework for use with children and adolescents who are nonverbal or have intellectual disabilities. For measures that assess physical function and activity participation in relation to chronic pain in children and adolescents with physical disabilities inclusion of assessments that are inclusive for activities across a spectrum of abilities is needed. There is also a need for assessments of types of chronic pain (i.e., neuropathic, visceral, central, and musculoskeletal). There is a need for validated measures that address change in chronic pain with interventions in children and adolescents.

<b>Instrument</b>	<b>Pain Categories</b>	<b>ICF Domain(s)</b>	<b>Classification</b>
Bath Adolescent Pain Questionnaire (BAPQ)	Interference	Activity and Participation	Supplemental
Body Diagram	Location and Intensity	Body Structure, Body Functions	Exploratory
Brief Pain Inventory (BPI) Long Form	Intensity, Interference, Location, and Quality	Body Structures, Body Functions, Activity and Participation	Supplemental
Brief Pain Inventory (BPI) Short Form	Intensity, Interference, and Location	Body Structures, Body Functions, Activity and Participation	Supplemental
Child Activity Limitations Interview (CALI)	Interference	Activity and Participation	Exploratory
Child Self Efficacy Scale-Child (CSES)	Self-efficacy and Interference	Activity and Participation	Exploratory
Face, Legs, Activity, Cry, Consolability Scale (FLACC)	Behavior	Body Structure, Body Functions, and Activities	Supplemental
Faces Pain Scale-Revised (FPS-R)	Intensity	Body Structures	Supplemental
Noncommunicating Children's Pain Checklist-Revised (NCCPC-R)	Behavior	Body Functions, Body Structures, Activity and Participation	Supplemental
Numeric Pain Rating Scale (NPRS)	Intensity	Body Functions	Supplemental
Pain Interference Index (PII)	Interference	Activity and Participation	Supplemental
Pediatric Pain Profile (PPP)	Interference and Behavior	Body Structures, Body Functions, Activity and Participation	Supplemental
Pediatric Pain Questionnaire (PPQ)	Intensity, Quality, and Location	Body Structures, Body Functions	Exploratory
PROMIS Pain Behavior Short Forms	Behavior	Body Functions	Exploratory
PROMIS Pain Interference Short Forms	Interference	Activity and Participation	Supplemental
Visual Analog Scale (VAS)	Intensity	Body Functions	Exploratory