**NINDS CDE Project**

**Working group: Neuromotor Skills and Functional Assessments**

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**Date: 8/10/2016**

1. **Approach for selection of elements:** We reviewed common data elements (CDE) and instruments that were included in disease groups. We then narrowed this to CDEs/instruments that we felt were applicable to Cerebral Palsy (CP). If an individual wasn’t sure about an element or instrument, this was discussed among the group with decision made by consensus. In addition, discussion among the group was held to identify areas or gaps in currently published CDEs. With regard to instruments, we searched systematic and narrative reviews to identify instruments that were deemed most reliable and psychometrically sound. When these reviews were not available (i.e., a newer instrument or an area that had few instruments), the literature was searched to identify the psychometric properties and intended instrument use/properties that the instrument measured. Instruments were selected based on psychometric soundness, use in CP, or instruments that were felt by the group to fill gaps in outcome measures/functional assessments, or were promising. With respect to CDE, when we could not identify a CDE that captured the information we felt was important, we created new elements.

Individuals and groups of 2–3 individuals with similar expertise were then assigned to create case report forms. The CRFs were created from the CDEs compiled. When possible, previously generated CRFs were used with alterations for language specific to CP. Creation of new CRFs were done when needed. Discussion was held among the group regarding the CRFs and the CDEs contained in the CRF. CRFs were reviewed among the group when questions would arise. Consensus was reached through discussion and review.

In addition, experts outside of our group were consulted with regard to recommendations and evidence regarding measures for the evaluation for infants and toddlers at risk of CP and diagnosis of CP. We would like to thank the following individuals for their assistance: Morgan C, Novak I, Adde L, Brunstrom-Hernandez J, Blackman J, Boyd RN, Cioni G, Damiano D, Darrah J, deVries L, Eliasson AC, Einspieler C, Fahey M, Fehlings D, Ferriero DM, Fetters L, Fiori S, Forssberg H, Gordon AM, Greaves S, Guzzetta A, Harbourne R, Hadders-Algra M, Kakooza A, Karlsson P, Krumlinde-Sundholm L, Latal B, Loughran-Fowlds A, Maitre NL, McIntyre S, Noritz G, Pennington L, Romeo D, Shepherd RB, Spittle AJ, Thornton M, Valentine J, Walker K, White R & Badawi N.

A particularly critical focus was made to identify and collate Occupational Therapy (OT), Physical Therapy (PT), and Speech and Language Pathology (SLP) CDEs and instruments. Specifically, OT, PT, and SLP CDEs were selected based on gaps and needs in rehabilitation research (specifically the need to determine the association between frequency, intensity, timing and type of rehabilitation intervention and outcomes), published literature, and clinical expertise. The CDEs and created CRFs were based on three key articles reviewed by three or more therapists in each discipline, and modified to reflect CP practice:

Effgen SK, McCoy SW, Chiarello LA, Jeffries LM, Bush H. Physical Therapy-Related Child Outcomes in School: An Example of Practice-Based Evidence Methodology. Pediatr Phys Ther. 2016;28(1):47–56.

Horn SD, Corrigan JD, Bogner J, Hammond FM, Seel RT, Smout RJ, Barrett RS, Dijkers MP, Whiteneck GG. Traumatic Brain Injury-Practice Based Evidence Study: Design and Patients, Centers, Treatments, and Outcomes. Arch Phys Med Rehabil. 2015;96(8 Suppl):S178–S196.e15.

Latham NK, Jette DU, Coster W, Richards L, Smout RJ, James RA, Gassaway J, Horn SD. Occupational therapy activities and intervention techniques for clients with stroke in six rehabilitation hospitals. Am J Occup Ther. 2006;60(4):369-78.

1. **Differential application to types of cerebral palsy** There are instruments/elements which are specific for spastic and dystonic CP, such as the Modified Ashworth Scale for spasticity and the Barry Albright Dystonia scale for dystonic CP or for specific GMFCS levels. If an instrument is specific for a type of CP or GMFCS level, this information is included in the Notice of Copyright Form.
2. **Summary recommendations** We reviewed instruments and CDEs applicable and inclusive of age (infant through 18 years) and type of CP. We also aimed to included CDEs and instruments for the diverse neuromotor skills areas of gross motor, speech and language, and fine motor which could be used for children across the developmental spectrum, functional abilities and among the CP types. Our focus was on diversity of instruments which have been shown to be psychometrically sound. We strongly felt that GMFCS should be considered a core element. Few instruments and CDEs were categorized as exploratory. Instruments and CDEs given this designation were either not validated in CP but filled a critical gap, or were new instruments with promise to fill a gap, or the instrument needs more psychometric property validation.
3. **Comparison to other cerebral palsy standards** Our CDEs are comparable to CDEs for other medical conditions. We used currently accepted terminology when drafting these based on published consensus statements of experts. Instruments were also sought from systematic reviews and narrative reviews in the CP literature, when those existed. OT, PT, and SLP recommendations are based on published data elements (modified to reflect CP practice), and are aligned with discipline specific standards of practice and current research.
4. **Issues unique to cerebral palsy**Cerebral palsy is a heterogeneous disorder in etiology and phenotype. Therefore, identifying instruments that spanned the CP type and functional ability were psychometrically sound, and specific to individuals with CP was challenging. As an extensive number of instruments have been used in CP, we felt it was critical to include those instruments with the best psychometric properties in the CP population, appearance of ongoing use (as determined by published papers), and of unique measurement properties.
5. **Unmet needs; unanswered questions** While there are well known spasticity and dystonia scales, we could not find instruments or scales to classify hypotonia. Our group also felt that we need more sensitive instruments to assess upper extremity functional capacity and change in children at GMFCS levels IV and V with bilateral cerebral palsy. We need to determine which aspects of rehabilitation intervention contribute to improved outcomes in children with CP at each GMFCS level, specifically with respect to dosage (frequency, intensity, timing and duration) and type of intervention or service. Lastly, we need to determine the impact that participation, as to how much the child engages during the session contributes to the outcomes of therapy and what is that optimal level. Lastly, we need to determine that measure that best reflects the function of the child when determining an intervention.

**Neuromotor Skill and Functional Assessments**

| **Classification** | **Functional Outcomes** | **Speech, Language and Communication** |
| --- | --- | --- |
| **Core** |  |  |
| **Supplemental – Highly Recommended** |  | * Peabody Picture Vocabulary Test 4th Edition (PPVT™-4) |
| **Supplemental** | * 10 Meter Timed Walk * 6 Minute Walk Test * Functional Mobility Scale * Functional Independence Measure for Children (WeeFIM) * Gait Deviation Index * Instrumented Gait Analysis * NIH Toolbox Walking Speed (4-Meter Walk Gait Speed Test) * Observational Gait Scale * Pediatric Evaluation of Disability Inventory (PEDI) * Pediatric Outcomes Data Collection Instrument (PODCI) * Stride Analysis and Gait Variability * Timed Up and Go (TUG) | * Clinical Evaluation of Language Fundamentals – Fifth Edition (CELF-5) * Clinical Evaluation of Language Fundamentals Preschool 2 (CELF Preschool 2) * Comprehensive Test of Phonological Processing, Second Edition (CTOPP-2) * Edinburgh Cognitive and Behavioural ALS Screen (ECAS) * Goldman-Fristoe Test of Articulation 2 (GFTA-2) * Language Sample Analysis * Percentage of Consonants Correct-Revised (PCC-R) * Preschool Language Scales – Fifth Edition (PLS-5) * Pure Tone Threshold Audiometry * Speech Language Profile Groups (SLPG) * Verbal Motor Production Assessment for Children (VMPAC) * Viking Speech Scale (VSS) |
| **Exploratory** | * Functional Independence Measure (FIM) * Goal Attainment Scale (GAS) | * Dynamic Evaluation of Motor Speech Skills (DEMSS) * Test of Children's Speech (TOCS) |

**Neuromotor Skill and Functional Assessments**

| **Classification** | **Classification** | **Motor Function** | **Spasticity/Movement** | **Trunk Control/Balance** |
| --- | --- | --- | --- | --- |
| **Core** |  |  |  |  |
| **Supplemental – Highly Recommended** | * Eating and Drinking Ability Classification System (EDACS) * Gross Motor Function Classification System-Expanded & Revised (GMFCS- ER) * Manual Ability Classification System * Communication Function Classification System (CFCS) | * Alberta Infant Motor Scale (AIMS) * Canadian Occupational Performance Measure (COPM) * Gross Motor Function Measure (GMFM-88, GMFM-66) * Prechtl's Assessment of General Movements [General Movement Assessments] * Test of Infant Motor Performance (TIMP) | * Barry Albright Dystonia Scale (BADS) * Tardieu Scale |  |
| **Supplemental** |  | * ABILHAND-Kids * Assisting Hand Assessment (AHA) * Melbourne Assessment 2:A Test of Unilateral Upper Limb Function * Quality of Upper Extremity Skills Test (QUEST) * Shriners Hospital for Children Upper Extremity Evaluation (SHUEE)Manual Muscle Testing- Using the Medical Research Council Muscle Grading Scale * Maximum Voluntary Isometric Contraction Testing (MVICT) | * Hypertonia Assessment tool (HAT) * Selective Control Assessment of the Lower Extremity (SCALE) | * Berg Balance Scale (BBS) * Functional Reach Test * Segmental Assessment of Trunk Control (SATCo) * Trunk Control Measurement Scale (TCMS) |
| **Exploratory** | * Bimanual Fine Motor Function (BFMF) | * Box and Blocks Test of Manual Dexterity * Jebsen Taylor Hand Function Test * Nine-Hole Peg Test (9-HPT) * Purdue Pegboard |  | * Early Assessment of Balance (EAB) * Level of Sitting Scale (LSS) |