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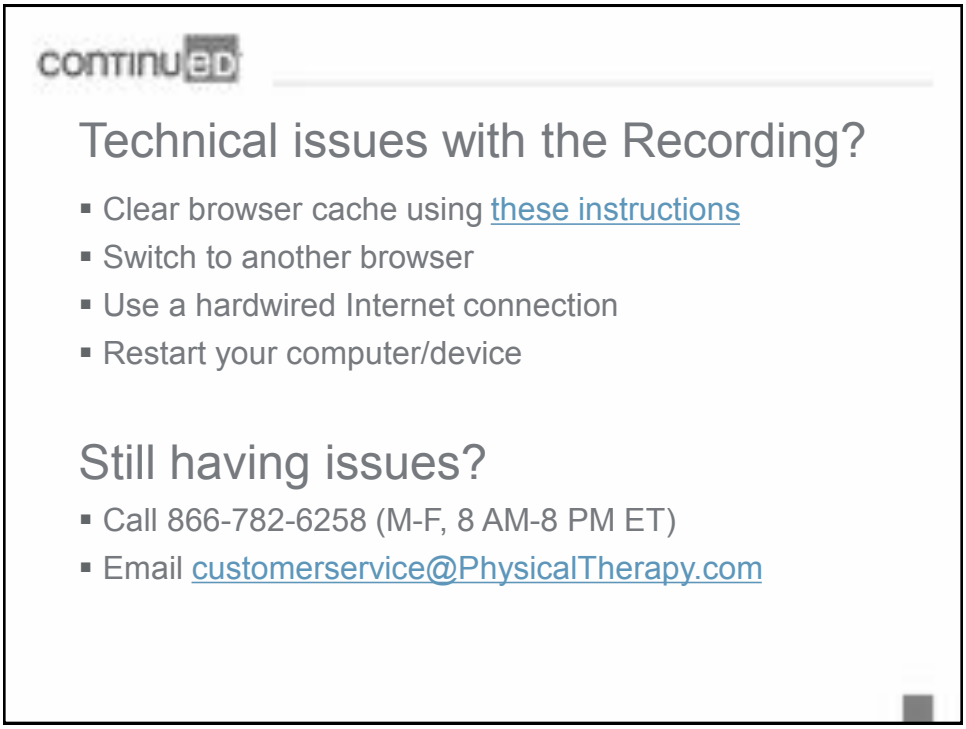
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Tools You Can Use: Enhancing Outcomes Assessment in Children with Cerebral Palsy

Lisa K. Kenyon PT, DPT, PhD, PCS

Learning Outcomes

After this course, participants will be able to:

- Utilize at least two evidence-based tools to classify the functional abilities of children with cerebral palsy.
- Discuss the use of at least three outcome measures for children with cerebral palsy that reflect the various domains of the International Classification of Functioning, Disability, and Health (ICF).
- Apply at least three evidence-based measures to monitor/track outcomes in children who have cerebral palsy.

Acknowledgment

Thank you to the families who have given their permission to show photographs of their children during this presentation.

Evidence-based Tools to Classify the Functional Abilities of Children with Cerebral Palsy

Classification of Function in CP

- Gross Motor Function Classification System (GMFCS)
- Manual Abilities Classification System (MACS)
- Communication Function Classification System (CFCS)
- Eating and Drinking Ability Classification System (EDACS)

Please Note

- The following tools (the GMFCS, MACS, CFCS, and the EDACS) are **not** outcome measures
- They are classification systems
  - Designed to recognize and distinguish varied levels of function in children with CP

The Gross Motor Function Classification System (GMFCS-ER)

The Gross Motor Function Classification System (GMFCS-ER)

- A 5 level classification system to describe the gross motor function of children and youth with cerebral palsy
  - Infants to 18th birthday
  - Based on self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility

GMFCS-ER

Distinctions between levels are based on functional abilities, the need for assistive technology, including hand-held mobility devices or wheeled mobility, and to a much lesser extent, quality of movement

GMFCS-ER

- Determine which level best represents the child's or youth's present abilities and limitations in gross motor function
  - Emphasis is on usual performance in home, school, and community settings (i.e., what they do)
  - NOT based on what they are known to be able to do at their best (capability)

GMFCS-ER: General Headings by Level

Level I: Walks without limitations

Level II: Walks with limitations

Level III: Walks using a hand-held mobility device

Level IV: Self-mobility limitations; may use power mobility

Level V: Transported in a manual wheelchair

GMFCS

- To download the various language versions of the GMFCS-ER at no cost: https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r
- Direct link to the English version: https://www.canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf

GMFCS-ER

Classify a child's function based on his/her current performance and gross motor function. DO NOT classify based on judgments about the quality of movement or prognosis for improvement

GMFCS-ER

- Allows for parent involvement in classifying their child's motor abilities
  - The GMFCS Family Report Questionnaire
  - Available for 3 age groups:
    - 2 to 4 years
    - 4 to 6 years
    - 6 to 12 years
    - 12-18 years (and self-report version!)
    - https://www.canchild.ca/system/tenon/assets/attachments/000/000/481/original/GMFCS_Family.pdf

Knowledge Translation & the GMFCS: Deville et al 2015

- Survey study of pediatric PTs
- 283 respondents
  - 100% had heard of the GMFCS
  - 95% agreed the GMFCS was useful
  - 81% reported they were confident in their ability to use the GMFCS
  - 77% reported they use the GMFCS

Knowledge Translation & the GMFCS: Deville et al 2015

- But…..

Knowledge Translation & the GMFCS: Deville et al 2015

- But…..Only 42% reported they use the GMFCS consistently

The Manual Ability Classification System (MACS)

The Manual Ability Classification System (MACS)

- A 5 level classification system to describe the ability of children with cerebral palsy to handle objects in daily activities
  - For children 4-18 years of age
  - Based on self-initiated manual ability with an emphasis on handling objects in an individual's personal space (those within reach)

MACS

- Can be used for children of different ages, but some interpretation is needed regarding the child's age
  - Example: Children handle objects differently at four years of age, compared to when they are adolescents
  - The same point concerns independence, as a young child needs more help and supervision than an older child
- Classification of a child should be made with reference to children of the same age

MACS

The focus of MACS is on determining which level best represents the child's usual performance in home, school and community settings

MACS

Distinctions between levels are made based on the child's ability to handle objects and the need for assistance or modifications

MACS: General Headings by Level

Level I - Handles objects easily and successfully

Level II - Handles most objects but with somewhat reduced quality and/or speed of achievement

Level III - Handles objects with difficulty; needs help to prepare and/or modify activities

MACS: General Headings by Level

Level IV - Handles a limited selection of easily managed objects in adapted situations

Level V - Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance

MACS

- To download the various language versions of the MACS at no cost: http://www.macs.nu/download-content.php
- Direct link to the English version: http://www.macs.nu/files/MACS_English_2010.pdf

The Mini-MACS

- To download the Mini-MACS for children ages 1-4 years at no cost: https://www.macs.nu/files/Mini-MACS_English_2016.pdf

Communication Function Classification System (CFCS)

CFCS

Does NOT consider perceived capacity, cognition, or motivation

CFCS

- Considers role as a sender and a receiver roles
- Looks at all methods of communication
  - Speech
  - Gestures
  - Behaviors
  - Eye gaze
  - Facial expressions
  - AAC systems

CFCS

Distinctions between levels are based on the performance of the sender and receiver roles, the pace of conversation, and the type of conversation partner

CFCS: General Headings by Level

Level I - Effective Sender and Receiver with unfamiliar and familiar partners

Level II - Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners

Level III - Effective Sender and Receiver with familiar partners

CFCS: General Headings by Level

Level IV- Inconsistent Sender and/or Receiver with familiar partners

Level V - Seldom Effective Sender and Receiver even with familiar partners

CFCS

- To download the various language versions of the CFCS at no cost: http://cfcs.us/?page_id=8
- Direct link to the English version: http://cfcs.us/wp-content/uploads/2014/02/CFCS_universal_2012_06_06.pdf

Gaining an Overall Picture of Function using the GMFCS, MACS, and CFCS

The GMFCS, MACS & CFCS for Children with Cerebral Palsy			
	GMFCS	**MACS**	**CFCS**
Level	**Mobility**	**Handling Objects**	**Communicating**
I.	Walks without limitations.	Handles objects easily and successfully.	Effective sender/receiver with unfamiliar and familiar partners
II.	Walks with limitations.	Handles most objects but with somewhat reduced quality and/or spread of achievement.	Effective but slower sender/receiver with unfamiliar and familiar partners
III.	Walks using a hand-held mobility device.	Handles objects with difficulty; needs help to prepare and/or modify activities.	Effective sender/receiver with familiar partners.
IV.	Self-mobility with limitations; May use powered mobility	Handles a limited selection of easily managed objects in adapted situations.	Inconsistent sender and/or receiver with familiar partners.
V.	Transported in a manual wheelchair.	Does not handle objects and has severely limited ability to perform even simple actions.	Seldom effective sender/receiver even with familiar partners

Cooley Hidecker et al 2012

- Investigated the relationships among the GMFCS, the MACS, and the CFCS in children with cerebral palsy (CP)
- Used questionnaires describing each scale
  - Mothers reported GMFCS, MACS, and CFCS levels

Cooley Hidecker et al 2012

- A clinic-based sample was recruited from child neurology, developmental/behavioral pediatric, or physiatry clinics in three cities in Michigan
  - Ann Arbor,
  - Grand Rapids
  - Lansing

Cooley Hidecker et al 2012

- Included 222 children with CP
  - 2 to 17 years of age
  - Types of CP
    - Hemiplegia n=45 (20%)
    - Diplegia n=66 (30%)
    - Quadriplegia n=85 (38%)
    - Not given n=26 (12%)

Cooley Hidecker et al 2012

- Correlations among the 3 functional assessments were strong or moderate
- GMFCS levels were
  - Highly correlated with MACS levels (rs=0.69)
  - Somewhat less correlated with CFCS levels (rs=0.47)
- MACS and CFCS were moderately correlated (rs=0.54)

Cooley Hidecker et al 2012

- Many combinations of functionality, however, were found
  - 125 possible combinations within the 3 different 5-point systems
    - 62 of these possible 125 combinations were found in these data.

The Eating and Drinking Ability Classification System

EDACS

- Purpose: To classify how individuals with CP eat and drink in everyday life
  - Provides a systematic way of describing an individual's eating and drinking in five different levels of ability

EDACS

- Focuses on the functional activities of eating and drinking
  - Sucking, biting, chewing, swallowing and keeping food or fluid in the mouth

EDACS

- Distinctions between the different levels in the EDACS are based upon functional ability, the need for adaptations to the texture of food and drink, the techniques used and some other features of the environment
  - Classifies overall performance in eating and drinking, including both motor and sensory elements

EDACS: General Headings by Level

- **Level I:** Eats and drinks safely and efficiently
- **Level II:** Eats and drinks safely but with some limitations to efficiency
- **Level III:** Eats and drinks with some limitations to safety; there may be limitations to efficiency

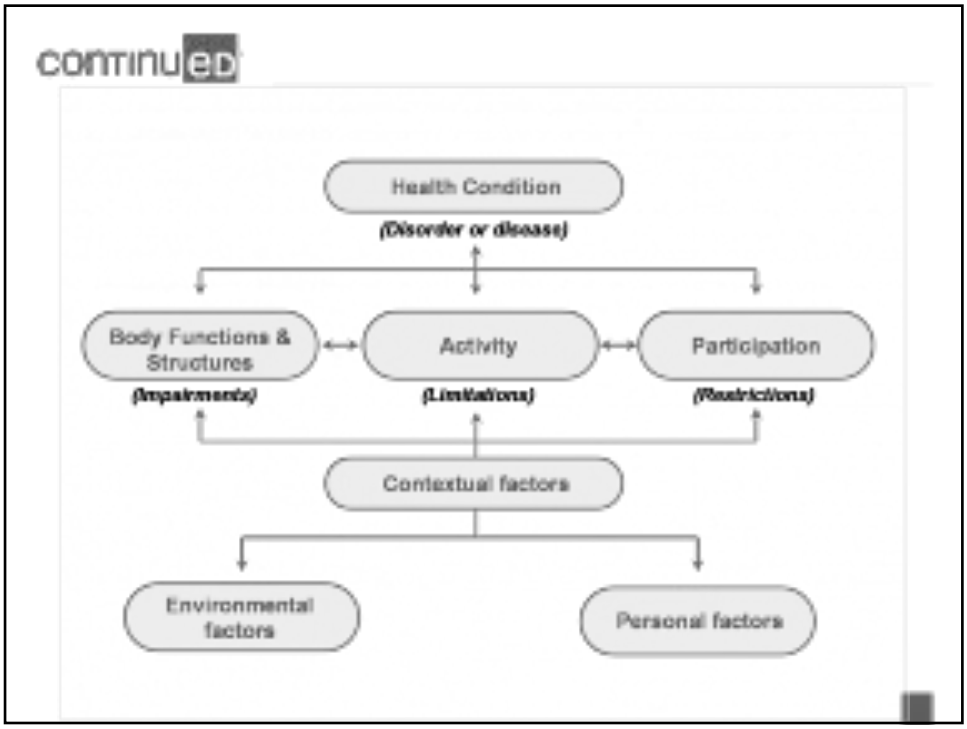
EDACS: General Headings by Level

- **Level IV:** Eats and drinks with significant limitations to safety.
- **Level V:** Unable to eat or drink safely – tube feeding may be considered to provide nutrition

EDACS

- To download the various language versions of the EDACS at no cost (must register first): https://www.sussexcommunity.nhs.uk/get-involved/research/chailey-research/eating-drinking-classification.htm
- Direct link to request the English version (must register first): https://www.sussexcommunity.nhs.uk/get-involved/research/chailey-research/edacs-request

Outcomes Measures Across the ICF for Children with CP



Select Test & Measures Reflecting the Body & Structure Level for Use with Children Who Have CP

The Spinal Alignment and Range of Motion Measure (SAROMM)

SAROMM

- https://canchild.ca/system/tenon/assets/attachments/000/002/581/original/SAROMMManualrev2018.pdf?license=yes

Overview of the SAROMM

The Spinal Alignment and Range of Motion Measure (SAROMM)

- A measure of posture and flexibility
- Intended for use in people with cerebral palsy
- Can be completed in 15 minutes with cooperative patients
  - 30 minutes might be required for those with more severe physical and cognitive impairments

SAROMM

- Equipment needed:

1. Firm sitting surface such that the patient is able to sit with the hips and knees both at approximately 90 degrees of flexion
2. Surface for testing in the supine position (floor or raised mat)

Note: If the patient is unable to attain or maintain bench sitting independently, may need 2 people to administer the test

SAROMM

- Consists of 2 subscales:
  - Spinal alignment
  - ROM and muscle extensibility

SAROMM

- Each subscale starts with observation of the patient's alignment and or limb posture
  - If "normal" or "optimal" alignment or posture is not observed, the patient is given up to 3 opportunities to actively correct to assume these positions

SAROMM

- If these optimal positions are assumed, a score of "zero" is given for these items
- If the patient cannot attain normal alignment through active movement, passive correction is conducted and the severity of the limitation is scored

Specifics of the Spinal Alignment Subscale

Spinal Alignment: Generic Procedure

The patient should be wearing shorts and either no top or a bathing suit top, halter top, or loose top to enable viewing of the spine

Spinal Alignment: Generic Procedure

- Items 1 to 4 are tested with the client sitting on a bench or chair with feet supported on the floor and with arms free, if able, or with support as necessary to prevent falling
  - Prior to the observation, ask the person to position themselves in their natural manner. Observe from side or back

Spinal Alignment: Generic Scoring Protocol

0 = "No alignment limitations with active correction"

1 = "Flexible - passive" - limitation is muscular and dynamic; limitation is reducible through passive movement

2 = "Fixed" - limitation is structural, static, not reducible and minimal

3 = "Fixed" – limitation is structural, static, not reducible and moderate

4= "Fixed" – limitation is structural, static, not reducible and severe

Spinal Alignment - Scoring Notes

- A score of "0" indicates
  - The person does not have a fixed alignment limitation
  - He or she can actively correct the alignment, even though the optimal alignment might not be the typical posture the person typically assumes

Spinal Alignment - Scoring Notes

- A score of "1" is used to indicate that the individual has good alignment on passive correction only

Spinal Alignment - Scoring Notes

- A score of "1" score is frequently given if the person does not assume optimal alignment after 3 requests to do so
  - Often occurs when examining someone with cognitive limitations
  - These individuals are at greater risk of subsequently developing permanent alterations in spinal alignment and range of motion and a score of 1 reflects this level of risk

Generic Procedure – Spinal Alignment Subscale

General Procedure

- Observe the child in sitting
  - If there aren't any alignment limitations, score a "0"
- If there are alignment issues, attempt to passively correct the alignment in each of the 4 areas

1 = "Flexible - passive" - limitation is reducible

2 = "Fixed" - limitation is not reducible - mild

3 = "Fixed" – limitation is not reducible - moderate

4= "Fixed" – limitation is not reducible - severe

Spinal Alignment: Generic Procedure

- For cases in which you cannot decide between one of two scores, document the "highest" score value
  - More severe limitations than that depicted in a specific figure should be scored at the higher value

Item 1: Cervical Spine in the Sagittal Plane - Sitting	Item 2: Thoracic Spine in the Sagittal Plane - Sitting	Item 3: Lumbar Spine in the Sagittal Plane - Sitting

Item 4: Spinal Alignment in the Frontal and Transverse Planes – Sitting

Specifics of the ROM and Muscle Extensibility

Range of Motion: Generic Scoring Protocol

0 "Normal" – no restriction of ROM on passive testing and no postures typical of some children with cerebral palsy observed **(note: both criteria are required, so passive testing is important to conduct for all items)**

1 "Flexible - passive" - postural limitation is muscular and dynamic; limitation is reducible through passive movement

2 "Fixed" - limitation is structural, static, and irreducible and is minimal

3 "Fixed" – limitation is structural, static, and irreducible and is moderate

4 "Fixed" – limitation is structural, static, and irreducible and is severe

SAROMM

For the range of motion items, if a person demonstrates posturing, passive range of motion is conducted and severity of limitation is rated according to specific criteria

Generic Procedure – ROM Items

- Start by observing the person's general movement for postures characteristic of some people with a diagnosis of cerebral palsy
- Therapists are familiar with postures such as hip flexion, adduction and internal rotation, knee flexion, and ankle plantarflexion

Generic Procedure – ROM Items

- Next, test passive range of motion (PROM)
  - If the person does not demonstrate postures assumed by some people with CP, and the PROM is full, score a "0"
  - If the person demonstrates these postures, and has full PROM, score a "1"
  - If the person does not have full PROM, score a "2", "3", or "4" if limitation is mild, moderate, or severe, respectively, as specified by individual criteria
  - For cases in which you cannot decide between one of two scores, document the "highest" number
    - For example, if you cannot decide if a person should get a "2" or a "3", record "3".

Determining End Range

- Move the limbs slowly and firmly so as to minimize the effect of spasticity
- For the most part, a firm end feel will be found as a result of a soft tissue stretch or a capsular stretch

  Examples:
  - Passive ankle dorsiflexion with the knee in extension (the movement is stopped by the tension in the gastrocnemius muscle)
  - Passive hip external rotation (the movement is stopped by the joint capsule of the hip)

Completing the Summary Score Sheet

Scoring Summary

- After completing the SAROMM, record the value for each of the items on the scoring summary sheet (page 1 of the score form)
  - Determine the Spinal Alignment Score by summing items 1 through 4
  - Record the mean value for this section by dividing the total score by 4

Scoring Summary

- Determine the
  - Hip score by summing items 5 through 16
  - Knee score by summing 17 through 20
  - Ankle score by summing 21 through 24
  - Upper extremity score by summing 25 and 26
- Determine the mean value for each of these scores
- Determine the Range of Motion Score by summing the hip, knee, ankle and upper extremity scores

Scoring Summary

- Determine the total SAROMM score by summing the Spinal Alignment and the Range of Motion Scores
- The mean values can be plotted on the graph on the last page of the scoring sheet for a visual representation of the information

Wright & Bartlett 2010

Distribution of Contractures and Spinal Malalignments in Adolescents with Cerebral Palsy: Observations and Influences of Function, Gender, and Age

Wright & Bartlett 2010

- Objective:
  - To describe distributions of contracture and spinal mal-alignment in adolescents with CP and to determine associations with age, gender, and function

Wright & Bartlett 2010

- Methods:
  - Participants were from publicly funded treatment centers
  - Data were collected using the Spinal Alignment and Range of Motion Measure (SAROMM), the Gross Motor Function Classification System (GMFCS), and the Activity Scale for Kids (ASK)

Wright & Bartlett 2010

- Results:
  - 225 adolescents (122 males, mean age 14yr 8mo, SD 1yr 8mo) participated
  - SAROMM scores by GMFCS levels and item scores in various body regions were presented

Wright & Bartlett 2010

- Results:
  - Correlations between indices of function and SAROMM total score were >0.70 ($p<0.001$)
    - Males in GMFCS Levels I/V obtained higher total SAROMM scores than females
    - Age was significantly associated with SAROMM scores for GMFCS Levels IV/V participants

Wright & Bartlett 2010

- Conclusions:
  - Gender and age were factors that modified outcomes
  - The data provide benchmarks for evaluating impairments in adolescents with CP and support the role of function in contracture development and possibly prevention

Wright, M, & Bartlett DJ. (2010). Distribution of contractures and spinal malalignments in adolescents with cerebral palsy: Observations and influences of function, gender and age. *Dev Neurorehabil*. 13(1), 46-52.

Functional LE Strength Tests

- 3 functional tests
  - Lateral Step-up
  - Sit-to-Stand
  - Transition: Half-Kneel to Stand

Verschuren O, Ketelaar M, Takken T, van Brussel M , Helders PJM, Gorter JW. Reliability of hand-held dynamometry and functional strength tests for the lower extremity in children with cerebral palsy. *Dis Rehabil*. 2008;30(18):1358-1366.

Functional LE Strength Tests

- Count the number of repetitions completed in a 30 second timeframe.
- Outside of the specifications for counting a repetition, quality of movement is not a consideration.

Functional LE Strength Test: Lateral Step-Up

- **Equipment Used:** A 20 centimeter (cm) bench, stop watch
- **Activity:** The child performs a lateral stepping technique
  - The child stands with the LE to be tested on the bench and the other foot on the floor. The feet are parallel and placed shoulder width apart
  - **The child steps up on the bench unilaterally X 30 seconds**
  - Appropriate lateral stepping technique is defined as the achieving a position within **15 degrees of full knee extension on the extremity being tested**
  - This test is performed bilaterally

Functional LE Strength Test: Lateral Step-Up

- Instructions to the Child:
  - The child is instructed in the activity and performs several slow practice repetitions to ensure understanding of the task
  - Then instructed to perform the lateral stepping as fast as he/she can until told to stop.

Functional LE Strength Test: Lateral Step-Up

- Scoring: Per the guidelines, repetitions of appropriate technique are counted each time the heel or toes of the extremity not being tested touches the floor.
- Units of Measurement: Number of repetitions

Functional LE Strength Test: Sit-to-Stand

- **Equipment Used:** A bench high enough for the child's feet to be flat on the floor with the hips and knees flexed to 90 degrees, stop watch.
- **Activity:** The child performs sit-to-stand transitions for 30 seconds without use of the UEs

Functional LE Strength Test: Sit-to-Stand

- **Instructions to the Child:**
  - The child is instructed in the activity and performs several slow practice repetitions to ensure understanding of the task
  - Then instructed to perform sit to stand transitions as fast as he/she can until told to stop.

Functional LE Strength Test: Sit-to-Stand

- **Scoring:** Per the guidelines, repetitions of appropriate technique are counted each time the child's legs and hips are within 15 degrees of the extended position
- **Units of Measurement:** Number of repetitions

Functional LE Strength Test: Transition Half-Kneel to Stand

- **Equipment Used:** Mat, stop watch
- **Activity:** The child performs transitions from half-kneel to stand for 30 seconds without using the upper extremities. This test is performed bilaterally

Functional LE Strength Test: Transition Half-Kneel to Stand

- **Instructions to the Child:**
  - The child is instructed in the activity and performs several slow practice repetitions to ensure understanding of the task
  - Then instructed to perform the transition as fast as he/she can until told to stop.

Functional LE Strength Test: Transition Half-Kneel to Stand

- **Scoring:** Per the guidelines, repetitions of appropriate technique are counted each time a standing position with both legs and hips within 15 degrees of the extended position is achieved
- **Units of Measurement:** Number of repetitions

10 x 5-m Sprint Test

- A test of agility
  - The ability to change direction in an effective and efficient.
- The subject performs a continuous sprint along the 5-m course until the 10 sprints have been completed.
  - 9 turns are executed during the test

Verschuren O, Takken T, Ketelaar M, Gorter JW, Helders PJM. Reliability for running tests for measuring agility and anaerobic muscle power in children and adolescents with cerebral palsy. *Pediatr Phys Ther*. 2007;19(2):108-115.

10 x 5-m Sprint Test

- **Equipment Used:** Cones, tape, stop watch
- **Set Up:** A 5-meter course is set up with cones and tape marking each end of the course
- **Activity:** The child performs a continuous sprint along the 5-meter course until the 10 sprints have been completed

10 x 5-m Sprint Test

- **Instructions to the Child:** Following the warm up activity, the child is instructed to run the continuous sprint as fast as possible.
- **Scoring:** A stop watch is used to record the time necessary for the child to complete each the continuous sprint. Time is recorded to the 10th of a second
- **Units of Measurement:** Seconds

10 x 5-m Sprint Test

Verschuren O, Bloeman M, Kruitwagen C, Takken T. Reference values for anaerobic performance and agility in ambulatory children and adolescents with cerebral palsy. *Dev Med Child Neurol*. 2010;52(10):e222-e228.

https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1469-8749.2010.03747.x

Select Test & Measures Reflecting the Activity Level for Use with Children Who Have CP

An Overview of the Gross Motor Function Measure

The GMFM

The GMFM was originally introduced in the late 1980s and included 88 items designed to evaluate change in motor function over time in children with cerebral palsy.

The GMFM

In 2002, the GMFM was updated and introduced in a 66 item format that was also designed to evaluate change in motor function over time in children with cerebral palsy.

The GMFM

Both versions of the GMFM (the GMFM-88 and the GMFM-66) are widely used in pediatric physical therapist practice. We will first discuss the GMFM-88, then discuss the GMFM-66.

The GMFM

The GMFM score sheet is available at the following Web site: https://canchild.ca/en/resources/320-gmfm-administration

The GMFM-88

The GMFM-88

- Designed to measure change in gross motor function in children with cerebral palsy
- Standardized for use with children with cerebral palsy

The GMFM-88

- A criterion-referenced measure
- Originally standardized for use in children 5 months to 16 years of age.
- Covers gross motor skills observed from birth to five years of age in children with typical development

The GMFM-88

- Appropriate for use in children or adolescents with cerebral palsy whose motor skills are at or below those of a typically developing five year-old.
- It has also been validated for use in children with Down Syndrome.

The GMFM-88

- Measures motor skills in five Dimensions
  - Lying and Rolling
  - Sitting
  - Crawling and Kneeling
  - Standing
  - Walking, Running and Jumping

The GMFM-88

- Each item is assessed using a four point ordinal scale from 0 to 3. Values are generally assigned as follows:

  0: Does not initiate the task being tested

  1: Initiates task (~10%)

  2: Partially completes task (10% - <100%)

  3: Completes the task as outlined

Score Sheet

The Score Sheet does not provide specific scoring criteria for each item. The test Manual is needed for the specific criteria for each item

The GMFM-88

- For each item, the child is allowed a maximum of 3 trials.
- Spontaneous performance of items are included in these three trials
  - The child cannot be given three trials and then later be scored on the spontaneous performance of the item.

The GMFM-88

- For the GMFM-88, any items not tested (for whatever reason) are scored as a zero.
  - This means if a child refuses an item, it is scored as a zero.

The GMFM-88

- Under certain criteria, the GMFM-88 can be performed with the child using aides and orthoses.
  - Administer the test first without use of aides or orthoses and then re-administer specific items as outlined in the manual with the child using the aides or orthoses

The GMFM-88

- Scores for the GMFM-88 are presented as a percentage for each Dimension and as a percentage for the total score of all items.
  - In a report, it is often helpful to present the results of the GMFM-88 in a table.

Example of Results in a Table:

Subtest	Raw Score	Percentage
Lying and Rolling	51/51	100%
Sitting	60/60	100%
Crawling and Kneeling	40/42	95.24%
Standing	32/37	82.05%
Walking, Running and Jumping	55/72	76.39%

The GMFM-88

- The GMFM-88 does not provide guidelines concerning the frequency of administration.
  - The GMFM-88 has been shown to be responsive to change over a six-month interval and is generally more responsive to change in younger children.

The GMFM-88

- Clinically important changes in percentage scores between administrations of the GMFM-88 will vary based on the perception of the child, the family, and the therapist
  - In the original validation work, parents and therapists identified a gain of 5-7 percentage points as a "medium" positive change

Advantages of the GMFM-88

- The measurement tool of choice for children
  - With severe motor disabilities (GMFCS Level V)
  - Very young children functioning primarily in the Lying and Rolling Dimensions
- Can be used for assessment of aids or orthoses

The GMFM-66

The GMFM-66

- Standardized for use ONLY with children with cerebral palsy
- Designed to measure change in gross motor function in children with cerebral palsy

The GMFM-66

- The GMFM-66 is an updated version of the GMFM-88 and in fact is the GMFM-88 minus 22 items!
- The items on the GMFM-66 were identified through Rasch analysis as being the best descriptors of gross motor function in children with cerebral palsy.

The GMFM-66

- GMFM-66 was developed secondary to limitations identified with the GMFM-88
  - Two children with the same percentage scores on the GMFM-88 can have very different scoring profiles and functional abilities
  - The large number of items on GMFM-88
    - Many children do not have the endurance or focus to complete all of the items on the GMFM-88

The GMFM-66

- The items are administered and scored in the same way as for the GMFM-88 EXCEPT that with the GMFM-66, it is important to differentiate between an item that is “Not Tested” and a true score of zero.
  - On the GMFM-66, children are not penalized with a score of zero when they refuse items

GMFM- 66 is **ONLY** for use with children with cerebral palsy

Score Sheet

The score sheet for the GMFM-66 is the same score sheet as for the GMFM-88. Items included in the GMFM-66 are marked on the score sheet with an asterisk.

The GMFM-66

- The GMFM-66 is scored via a computer program called the Gross Motor Ability Estimator – 2nd edition (GMAE – 2)
  - The GMAE converts scores and plots them on an interval scale of gross motor function as opposed to the ordinal scale used in the GMFM-88

The GMFM-66 cannot be scored without the GMAE

GMAE Downloads

GMAE-2:

https://canchild.ca/en/resources/191-gross-motor-ability-estimator-gmae-2-scoring-software-for-the-gmfm

GMAE-3: Available through the GMFM App+

https://www.canchild.ca/en/shop/38-the-gross-motor-function-measure-app

The GMFM-66

- The GMFM-66 does not provide guidelines concerning the frequency of administration.
  - The responsiveness of the GMFM-66 has been shown to be similar to that of the GMFM-88 over a period of six and twelve months.

Advantages of GMFM-66

- There are fewer items than on the GMFM-88
- If child refuses an item, there is no penalty like there is in the GMFM-88
- GMFM-66 scores have interval properties
  - Allows for comparison of change between children
- GMFM-66 is the measurement of choice for research involving children with cerebral palsy

Abbreviated Versions of the GMFM-66

GMFM-66: Two Short Forms of Administration

GMFM-66 B & C and GMFM-66 IS

https://canchild.ca/en/resources/320-gmfm-administration

GMFM-66 B & C

GMFM-66 B&C

- Uses a basal and celling level approach
  - Similar to the approach used in the PDMS-2
- Basal = 3 successes in row established at the start of the test
- Ceiling = 3 zeros in a row indicates that testing has ended

GMFM-66 B&C

- Minimum of 15 items must be administered
  - If ceiling is reached before 15 items are tested:
    - One easier item and one harder item are alternately administered and scored until a total of 15 items have been tested
- Scoring of children in GMFCS level I should start at Item 79

GMFM-66 IS

GMFM-66-IS

Uses a scoring algorithm in which a number of "decision items" to guide the therapist toward a predetermined set of items relevant to a child at the established functional level

GMFM-66-IS

- The GMFM-66-IS is the preferred abbreviated version for children who have “unilateral” CP
  - Seeing more and more of the terms “unilateral” CP and “bilateral” CP

Using the Abbreviated Versions

- Both abbreviated versions are reliable and valid
  - If the primary goal of assessment is to measure change over time, the complete GMFM-66 should be considered the criterion standard

Motor Growth Curves

Motor Growth Curves

- Describe the patterns of motor development, grouped by GMFCS level
  - Concept is similar to the growth charts that are used to follow the height and weight of children as they grow
- Designed to
  - Help understand how the gross motor abilities of children in each level change with age
  - Estimate a child's future motor capabilities including how much independence children are likely to achieve

Motor Growth Curves

- Present a plot of GMFM-66 scores (on the vertical axis) by age (across the horizontal axis) for each of the 5 GMFCS levels.
- A child's relative ranking compared to children in the population-based sample can be determined.
  - With repeated scoring over time, it is possible to determine whether a child is functioning as well as expected, better than expected or more poorly then expected

Tabulated Reference Percentiles

- When referencing a particular child's motor performance:
  - Find the table for his or her GMFCS level
  - Scan across the row that is closest to this child's age, and find the number that is closest to his or her GMFM-66 score.
  - The corresponding column heading gives the child's approximate percentile score, which is the percentage of children in the normative sample that this child is expected to outperform.

Tabulated Reference Percentiles

- Remember….unlike raw GMFM-66 scores, which measure motor ability, GMFM-66 percentiles measure *only relative ability compared with other children of the same age and GMFCS*

Age by Which Children with CP Typically Are Expected to Reach 90% of Their Motor Developmental Potential

GMFCS level	Age in years
I	4.8 years
II	4.4 years
III	3.7 years
IV	3.5 years
V	2.7 years

Trends…..

- There is a tendency for children with lower motor development potential to reach their limit more quickly

Caveats….

- Only for use with children with CP
- Children who function at a GMFCS Level II or IV may be at a disadvantage when their GMFM-66 scores are plotted on the Motor Growth Curves…. Why?

Caveats….

- Must consider whether the normative sample is appropriate for your child
- When evaluating percentile change over time, it is typical for percentile scores to vary widely on re-assessment and this may not reflect change in ability.

Motor Growth Curves

Rosenbaum P, Walter S, Hanna S, Palisano R, et al. Prognosis for gross motor function in cerebral palsy: Creation of motor development curves. *JAMA*. 2002;288(11):1357-1363.

https://canchild.ca/system/tenon/assets/attachments/000/000/999/original/PrognosisforGrossMotorFunction.pdf

Tabulated Reference Percentiles

Hanna SE, Bartlett DJ, Rivard LM, Russell DJ. (2008). Reference curves for the Gross Motor Function Measure: Percentiles for clinical description and tracking over time among children with cerebral palsy. *Phys Ther*. 2008;88(5):596 - 607.

https://canchild.ca/system/tenon/assets/attachments/000/000/222/original/tabulated_gmfm66_percentiles.pdf

GMFM App+

- App that includes the Gross Motor Ability Estimator
- Enter scores for the GMFM-88, GMFM-66, GMFM Item Sets, and GMFM Basal and Ceiling version
  - GMFM-88 dimension and total scores
  - GMFM-66 scores calculated using the GMAE-3

GMFM App+

- Provides:
  - Spider charts of GMFM-88 scores
  - Individual items scores and GMFM-66 scores with 95% Confidence Intervals on Item maps
  - Maps GMFM-66 scores on Motor Growth Curves

GMFM App+

Available versions include Single-User for PC and Mac computers. Coming soon: Android and iOS

https://www.canchild.ca/en/shop/38-the-gross-motor-function-measure-app

The CHALLENGE Module

The Challenge Module

- An assessment of advanced motor skills
- Designed to extend upon the foundation skills of the GMFM
- For use with children with CP who are:
  - Ages 6 years and up
  - Ambulatory without devices
    - Function at GMFCS Level I or II

The Challenge Module

- Test skills that are considered important for children and youth to be able to perform in school and recreation
- Focuses on speed, balance, coordination, integration of upper and lower limb movements, and dual task performance

The Challenge Module

- Consists of 20 items
- Scored on a 5-point response scale, 0 to 4, using item-specific response options.
- Administration takes 45 to 60 minutes
- Requires a 10 meter 'track'

The Challenge Module

- Requires certification
- https://research.hollandbloorview.ca/what-challenge

An Overview of the Timed Up & GO (TUG)

Timed Up & Go (TUG)

- Used to assess functional ambulatory mobility and dynamic balance
- Easy to administer - does not require specific training or special equipment

Timed Up & Go (TUG)

Classically, administration involves measuring the amount of time it takes for an individual to go from sitting in a chair, to standing up and walking 3 meters, turning around, walking back to the chair, and sitting in the chair

Timed Up & Go (TUG)

- In children, the administration protocol has been adjusted by using a chair with or without arm or backrests, with and without shoes, with and without orthotics, etc.
- Most authors suggest that the TUG should be explained and demonstrated to a child before actual administration

Psychometrics of the TUG in Children

- Excellent intra-rater reliability
  - Intraclass correlation coefficient [ICC] = 0.99, age 8-14 years) and inter-rater reliability (ICC = 0.99, age 4-11 years and age 8-14 years) and very good test-retest reliability (ICC > 0.83, age 7-14 years, age 4-11 years, and age 3-9 years
- TUG scores correlate moderately to strongly with the Gross Motor Function Measure-88 items (r = –0.524, $P < .019$; r = –0.89, $P < .015$)

Psychometrics of the TUG in Children

- The TUG discriminates between Gross Motor Function Classification System levels I, II, and III
- Reference values are available
- Cur scores based on z scores are available for children of various ages
- There is even a modified TUG for preschool aged children

Timed Up & Go (TUG)

Reference data for school-aged children:

Itzkowitz A, Kaplan S, Doyle M, Weingarten G, Lieberstein M, Covino F. Timed Up and Go: reference data for children who are school age. *Pediatr Phys Ther*. 2016;28(2):239-246.

, https://journals.lww.com/pedpt/Fulltext/2016/28020/Timed_Up_and_Go__Reference_Data_for_Children_Who.25.aspx

Functional Mobility Scale (FMS)

Walking Distance	Rating (1-6)
5 yards	
50 yards	
500 yards	

RATING	DESCRIPTION
1	Uses a WC – may stand for transfers or step with assist of another person
2	Uses a walker without help from another person
3	Uses crutches without help from another person
4	Uses sticks/poles/canes (1 or 2) without help from another person
5	Independent on level surfaces – requires a rail for stairs
6	Independent on all surfaces (uneven ground, curbs, crowded environments, etc.)

Functional Mobility Scale (FMS)

Link to Measure:
https://www.schn.health.nsw.gov.au/files/attachments/the_functional_mobility_scale_version_2.pdf

The Chailey Levels of Ability

- Documents stages of motor development in the prone, supine, floor sitting, box sitting, and standing.
- Observational scale
  - Match the components achieved with the provided list
  - Record the highest corresponding level of ability
  - All indicated components at the assigned level must be present
  - Some components may be observed but are not essential when scoring a level of ability

Example: Chailey Box Sitting- Level 2

- Child can be placed in a sitting position
- Needs support (needs to be held) to stay in position
- Trunk can be brought forward over the sitting base
- Pelvis is posteriorly tilted
- Shoulder girdle is retracted or in neutral
- The back is rounded

Example: Chailey Standing- Level 7

- Able to stand independently by releasing hands from support for a few seconds
- Able to leave position without support
- Standing base as wide or slightly wider than pelvis
- Arms in medium to high guard position
- Toe grasping

The Chailey Levels of Ability

Link to Measure:

http://wiredspace.wits.ac.za/bitstream/handle/10539/10581/Appendix%20G%20-%20Chailey%20Assessment%20Charts.pdf?sequence=5

Select Participation Level Measures

The Participation and Environment Measure for Children and Youth

PEM-CY

- A parent-report measure designed to help parents, service providers and researchers better understand the participation of children and youth ages 5 to 17
  - First measure that assesses participation and environmental factors at the same time

PEM-CY

- Measures participation in the home, school and community
  - And environmental factors within each of these settings
- Available at: https://canchild.ca/en/shop/2-pem-cy-participation-and-environment-measure-children-and-youth

The Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD)

CPCHILD

- Measures caregivers' perspectives on the health status, comfort, well being, functional abilities and ease of caregiving of children with severe developmental disabilities
  - Can be used for children with severe disabilities who do not have CP!
- Developed to measure the effectiveness of interventions intended to improve or preserve these outcomes for children with severe disabilities

CPCHILD

- Link to manual and scoresheet: http://www.sickkids.ca/pdfs/Research/CPChild/6573-CPCHILD_manual.pdf

Other Potential Measures

PEDI-CAT

- Measures abilities in three functional domains: Daily Activities, Mobility and Social/Cognitive plus the Responsibility domain
- Can be used with all clinical diagnoses and across all settings
- Parent report OR clinicians or educators who are familiar with the child

PEDI-CAT

- Uses Item Response Theory (IRT) statistical models to estimate a child's abilities from a minimal number of the most relevant items or from a set number of items within each domain
- Each domain starts with a mid-range item
  - The item that comes next will be a harder or easier item depending on the response to the first

PEDI-CAT

- Available for purchase at: https://www.pedicat.com/portfolio/

Other Potential Tests & Measures

- The Canadian Occupational Performance Measure and Goal Attainment Scaling
  - Provide a framework for developing patient/client centered functional goals that can then be objectively assessed.
- Functional goals typically reflect the Activity or participation Domains of the ICF.

Goal Attainment Scaling

- http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=1263
- http://elearning.canchild.ca/dcd_pt_workshop/assets/planning-interventions-goals/goal-attainment-scaling.pdf

COPM

http://www.thecopm.ca/

Early Identification of Cerebral Palsy in Young Infants

JAMA Pediatrics | Review

Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy
Advances in Diagnosis and Treatment

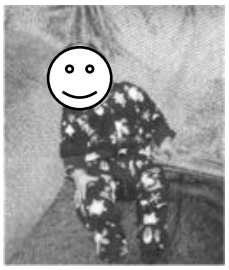
Iona Novak, PhD; Cathy Morgan, PhD; Lars Adde, PhD; James Blackman, PhD; Roslyn N. Boyd, PhD; Janice Brunstrom-Hernandez, MD; Giovanni Cioni, MD; Diane Damiano, PhD; Johanna Darrah, PhD; Ann-Christin Eliasson, PhD; Linda S. de Vries, PhD; Christa Einspieler, PhD; Michael Fahey, PhD; Darcy Fehlings, PhD; Donna M. Ferriero, MD; Linda Fetters, PhD; Simona Fiori, PhD; Hans Forssberg, PhD; Andrew M. Gordon, PhD; Susan Greaves, PhD; Andrea Guzzetta, PhD; Mijna Hadders-Algra, PhD; Regina Harbourne, PhD; Angelina Kakooza-Mwesige, PhD; Petra Karlsson, PhD; Lena Krumlinde Sundholm, PhD; Beatrice Latal, MD; Alison Loughran-Fowlds, PhD; Nathalie Maitre, PhD; Sarah McIntyre, PhD; Garey Noritz, MD; Lindsay Pennington, PhD; Domenico M. Romeo, PhD; Roberta Shepherd, PhD; Alicia J. Spittle, PhD; Marelle Thornton, DipEd; Jane Valentine, MRCP; Karen Walker, PhD; Robert White, MBA; Nadia Badawi, PhD

Early Diagnosis of CP

- Historically, a diagnosis of CP was made 12-24 months of age
- Now can be made **BEFORE** 6 months' corrected age

Sensitivity and Specificity

- **Sensitivity** reflects of how many patients with the diagnosis test positive
- **Specificity** is a measure of the false positive rate



- SPIN: With high specificity, a positive test rules in the diagnosis
- SNOUT: with high sensitivity, a negative test rules out the diagnosis

JAMA Pediatrics | Review

Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy
Advances in Diagnosis and Treatment

- Before 5 months' corrected age, the most predictive tools for detecting risk are:
  - Term-age magnetic resonance imaging (86%-89%sensitivity)
  - The Prechtl Qualitative Assessment of General Movements (98% sensitivity)
  - The Hammersmith Infant Neurological Examination - HINE (90% sensitivity)

JAMA Pediatrics | Review

Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy
Advances in Diagnosis and Treatment

- After 5 months' corrected age, the most predictive tools for detecting risk are:
  - Magnetic resonance imaging (86%-89% sensitivity)
    - Where safe and feasible
  - The Hammersmith Infant Neurological Examination - HINE (90% sensitivity)
  - The Developmental Assessment of Young Children (83%C index)

Hammersmith Infant Neurological Examination (HINE)

- Infants 2-24 months of age
- 26 items
  - Cranial nerves
  - Posture
  - Movements
  - Tone
  - Reflexes
- Good interobserver reliability (even in inexperienced raters)

Hammersmith Infant Neurological Examination (HINE)

- Infants 2-24 months of age
- 26 items
  - Cranial nerves
  - Posture
  - Movements
  - Tone
  - Reflexes
- Good interobserver reliability (even in inexperienced raters)
- TIME: 5-10 minutes

HINE

- Each item is scored on ordinal scale from 0 to 3
- Individual scores are added together to achieve a global optimality score
- This global score can range from
  - A minimum of 0 (if all the items are scored as a 0)
  - A maximum score of 78 (if all the items are scored as a 3)

HINE

- Each item is scored on ordinal scale from 0 to 3
- Individual scores are added together to achieve a global optimality score
- This global score can range from
  - A minimum of 0 (if all the items are scored as a 0)
  - A maximum score of 78 (if all the items are scored as a 3)

HINE

- The HINE can be used to reliably assess infants at neurological risk
  - Both infants born preterm and at term
- The HINE identifies early signs of CP in infants with neonatal brain lesions
- Longitudinal assessments will allow differentiation of transient and more permanent abnormalities

HINE

- Register for free: http://hammersmith-neuro-exam.com/

Review the Objectives:
Any Questions?
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