Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

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Today’s Focus

1. Describing the Research Problem
2. Creating the Communication Function Classification System (CFCS) for individuals with cerebral palsy
3. Using the CFCS
4. Discussing Next Steps
Cerebral Palsy Definition

“describes a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disturbances of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems” Rosenbaum, et al. (2007)
Cerebral Palsy Definition

Annotations of each term follow, including:

“‘sensation’ – Vision, hearing and other sensory modalities may be affected, both as a function of the ‘primary’ disturbance(s) to which CP is attributed, and as a secondary consequence of activity limitations that restrict learning and perceptual development experiences.”

“‘communication’ – Expressive and/or receptive communication and/or social interaction skills may be affected, both as a function of the ‘primary’ disturbance(s) to which CP is attributed, and as a secondary consequence of activity limitations that restrict learning and perceptual development experiences.”

Rosenbaum, et al. (2007)
Cerebral Palsy

- Affects 1 in 500 children born each year
  
  Stanley et al. (2003), Odding et al. (2006), Paneth et al. (2006)

- Lifetime cost estimated at $1 million per individual with CP
  

- Clinical diagnosis by physician (often a neurologist)
  
  - Gross & fine motor problems
    
    - Resulting from non-progressive neural damage to the baby during pregnancy and perinatal period
  
  - There is no specific biomedical test for CP
Cerebral Palsy Classifications

By type of movement

- Spastic CP
  - Stiff, contracted muscles
  - 70 to 80%
- Athetoid or dyskinetic CP
  - Uncontrolled, slow, writhing movements
  - 10 to 20%
- Ataxic CP
  - Walk unsteadily
  - Poor coordination and balance
  - 5 to 10%
- Mixed forms

By type of tone

- Hypertonicity
  - Stiff, rigid
- Hypotonicity
  - Floppy, loose
- Changing

By limb involvement

- Hemiplegia
  - Arm & Leg on same side of body (R or L)
- Diplegia
  - Arms and Legs but legs more involved
- Quadriplegia or Tetraplegia
  - Arms and Legs equally involved OR Arms more involved than legs

Remaining terms describe rare limb patterns

- Monoplegia
  - One limb
- Triplegia
  - Three limbs
- Paraplegia
  - Only legs involved
WHO ICF Model

The World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF)

WHO, 2002
WHO ICF Model: 3 perspectives on assessment and intervention

1. **body structure and function** – anatomy & physiology includes language subsystems
2. daily **activities** – carrying out tasks such as communication
3. **participation** in home, school, work and/or community

- Also consider interactions with
  - **personal** factors (e.g., age, motivation, desires) and
  - **environmental** factors (e.g., settings of home or community, familiarity with communication partner)
The Speech Chain = ICF Body/Structure Function Level

FIGURE 1.1  The speech chain: the different forms of a spoken message in its progress from the brain of the speaker to the brain of the listener.

Denes & Pinson, p.5
The Communication Model
= ICF Activities/Participation Levels

Sender

Message

Receiver

Communication Environment
How many individuals with CP have communication problems?

- “Up to 80%...have at least some impairment of speech” Odding, et al (2006)

- Flawed numbers for a variety of reasons
  - No indication of the basis for the numbers
    - 30% have “hearing, speech, and language impairments” Pellegrino (2002)
  - No operational definitions
  - Confusing definitions
    - Hearing “> 70 decibels in better ear” Colver & SPARCLE (2006)
How many individuals with CP have communication problems?

- Few recent studies conducted by SLPs and audiologists
  - Many citations are based on published U.S. research in 1950’s and 1960’s
  - Need for CP epidemiological studies of communication and eating
    - In U.S., no national registry of individuals with CP
    - Expensive research to carry out and maintain
    - Need for multidisciplinary teams
Few Communication Measures in CP Studies

- **Need**: Better measures of speech, language, and hearing within existing CP epidemiological studies.

- **Challenge**: Quick, multidisciplinary measure of communication

- **Hope**: More SLPs and audiologists will be included on CP research teams
Functional Limitations in Daily Activities may include:

- Mobility
  - Gross Motor Function Classification System (GMFCS)
    [www.canchild.ca/Portals/0/outcomes/pdf/GMFCS.pdf](http://www.canchild.ca/Portals/0/outcomes/pdf/GMFCS.pdf)

- Handling Objects

- Communication
  - Communication Function Classification System (CFCS) in validation and reliability phases

- Eating/Drooling
  - ????????
Purpose of CFCS research

- To create a communication classification to be used in CP research and clinical settings
  - Must be grounded in speech-language pathology and audiology literature
  - Must be understandable to all interested in CP
  - Must be valid and reliable, yet short enough to be easily added to long protocols of measurements in multidisciplinary studies
  - Will not replace existing communication assessments
Research Aims

Using an interdisciplinary research approach,
1. Create descriptions for each CFCS level.
2. Examine content validity using nominal group and Delphi survey methodology.
3. Measure inter-rater and intra-rater reliability of the CFCS among professional and lay team measures.
4. Produce a final version of CFCS suitable for cerebral palsy clinical and research settings.
Participants from 8 stakeholder groups

1. Adults with CP
2. Parents of children with CP
3. Educators
4. Neurologists
5. Occupational Therapists
6. Pediatricians
7. Physical Therapists
8. Speech-Language Pathologists
Method

4 Phases:

1. Development
2. Nominal groups
3. Delphi surveys
4. Reliability studies
Development Team Members

1 Adult with CP/Educator
1 Parent of children with CP
1 Neurologist
2 Occupational Therapists
2 Pediatricians
1 Physical Therapist
+ 3 Speech-Language Pathologists
11 Development Team Members
Nominal Group Process:
3 to 4 hr discussions on CFCS

- 27 participants (4 small groups)
  - 19 Females
  - 8 Males
  - 26 Caucasians
  - 1 Pacific Islander

- Educational Background
  - 7% High School degree
  - 26% College degree
  - 67% Some grad school or advanced degree

- Years of CP Experience
  - 8% <5 years
  - 11% 5-10 years
  - 81% +10 years

- Type of Experience with CP
  - 11% Adult with CP
  - 15% Parent
  - 15% Educator
  - 7% O.T.
  - 15% Physician
  - 11% P.T.
  - 26% SLP
  - 15% Other
Nominal Group Process: Participant Demographics

- Aware of communication disorders with CP?
  - 89% aware of hearing Loss
  - 85% aware of receptive communication disorders
  - 85% aware of expressive communication disorders
  - 100% aware of motor speech disorders

- Familiar with augmentative and alternative communication (AAC)?
  - 4% were not familiar with AAC
  - 70% had seen people using AAC
  - 48% work with AAC users
  - 15% have family members that use/had use AAC
  - 4% use AAC/had used AAC in past
Current CFCS draft

- 5 everyday communication performance levels
  
  I. **Effective Sender & Receiver** with unfamiliar and familiar partners
  
  II. **Effective Sender & Receiver**, but **slower conversational pace**, with unfamiliar and familiar partners
  
  III. **Effective Sender & Receiver** with familiar partners
  
  IV. **Sometimes Effective** Sender & Receiver with familiar partners
  
  V. **Seldom Effective** Sender & Receiver with familiar partners
CFCS Level Identification Chart

Does the child consistently and effectively alternate sender and receiver roles?

Yes → Does the child usually maintain a natural conversational pace with communication partners?

Yes → Level I Effective Sender and Receiver with unfamiliar and familiar partners

No → Level II Effective, but slower, Sender and/or Receiver with unfamiliar and familiar partners

No → Is the child an effective sender AND/OR a receiver at least some of the time?

Yes → Level III Effective Sender AND Effective Receiver with familiar partners

No → Level IV Sometimes Effective Sender and/or Effective Receiver with familiar partners

No → Level V Seldom Effective Sender and Receiver with familiar partners

Please do not use without permission.
Using the current CFCS

- Use the CFCS to classify the following video clips

- If you are willing to turn in your classifications anonymously, we would be interested to see how people use the system.
Current CFCS draft

- [YouTube](http://youtube.com/watch?v=IFMLL6A7K0U) Josh
- [YouTube](http://www.youtube.com/watch?v=fAdEOXD9TvK) Ellen
- [YouTube](http://www.youtube.com/watch?v=WG_UjzYmypA) Jenna 4 yr
- [YouTube](http://youtube.com/watch?v=CiHxAQhkijk) Bryclen age 10?
- [YouTube](http://youtube.com/watch?v=IUSk5RiFNUc) 26 yr old F
- [YouTube](http://www.youtube.com/watch?v=V1C8G5nNE7k) Sara
Current CFCS draft

- What is not clear?
- What do you like?
- Any other suggestions or comments?
Issues

- Age bands? Does age appropriateness interact with effective communication?
- Separate (optional) subscales for sender and for receiver?
- Unfamiliar/familiar partners treated as categories, probably more along a degree of familiarity?
- Environmental demands?
Want to be Involved?

- Email CFCS Project Coordinator Brenda Johnson at cfcs@epi.msu.edu to:
  - Join our Listserv!
    - Find out what is going on with CFCS research via occasional emails
  - Participate in Delphi Survey and/or Reliability Studies.
  - Encourage others to participate in Delphi Survey and/or Reliability Studies.
Participants Needed

Recruiting adults interested in cerebral palsy (CP) including: Adults with CP, Educators, Neurologists, Occupational therapists (OTs), Pediatricians, Physical therapists (PTs), Speech-language pathologists (SLPs), & Parents of children with CP

See details at
http://www.msu.edu/~hidecke1/Delphi_Survey_Study.pdf

http://www.msu.edu/~hidecke1/ReliabilityStudy.PDF

For more information, please contact
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Clinical Implications - examples

- Knowing a person’s CFCS classification may suggest a starting point for intervention (need clinical evidence)
  - Level I – Any activity or participation limitations? Decrease any residual speech sound errors?
  - Level II – Any ways to speed up communication, especially with unfamiliar partners?
Clinical Implications – examples

- Level III – Increase communication partners? Improve communication repair strategies?
- Level IV – Increase sender and/or receiver skills?
- Level V – Improve partner recognition of gestures and unconventional messages?
  - Focus on communication partner training.
  - Create a communication dictionary of these unconventional message.
  - Pair AAC message with unconventional message.
Future research directions

- Create a snapshot of a person’s functional levels by reporting the CFCS in conjunction with GMFCS & MACS.
- Correlate the CFCS level to body structure/function measures of speech, language, & hearing.
- Correlate the CFCS level to quality of life and/or participation measures.
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