# *Cerebral palsy and speech-language pathology research collaborations: Valuing multiple perspectives*

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# 3 aims

1. Need for speech-language pathologists and audiologists to be on CP research teams
   - Speech language pathology expertise areas
   - Audiology expertise areas
2. CFCS – valuing multiple perspectives
3. Research collaborations in cerebral palsy research

# Areas relevant to CP:
## ICF Body Structure & Function

- **Speech subsystems**
  - Respiration
  - Phonation
  - Resonance
  - Articulators
- **Language components**
  - Receptive/expressive
  - Pragmatics
    - Why we communicate
  - Semantics
    - What words we use
  - Syntax, Morphology, Phonology
    - How we use grammar, word parts, & sounds
- **Hearing/balance subsystems**
  - Peripheral auditory system
    - Outer
    - Middle
    - Inner
    - Auditory pathway
  - Central auditory system
  - Vestibular system
- **Swallowing subsystems**
  - Oral preparation
  - Oral stage
  - Pharyngeal stage
  - Esophageal stage

# **Areas relevant to CP:**
## ICF Activity & Participation

- **Activity**
  - Communication
  - Eating
  - Learning
- **Participation**
  - At Home
  - At School
  - At Work
  - In the Community
  - **Not discipline specific**

# Areas relevant to CP:
## ICF Environmental Factors

- **Communication Partners**
  - Unfamiliar to Familiar

- **Physical Settings**
  - Conducive to communication?
    - Background Noise?
    - Proximity?
    - Lighting?

# Communication Function Classification System (CFCS) experience

- **Developed with multiple perspectives**
  - Adults with CP
  - Educators
  - Occupational therapists
  - Parents of children with CP
  - Physical therapists
  - Physicians
  - Speech-language pathologists
- **Including adults with cerebral palsy and family members**

- **Important to develop a common language**
  - Improve upon no, mild, moderate, or severe labeling

- **Family of classifications**
  - **ICF Activity & Participation Levels**
    - **GMFCS**
    - **MACS**
    - **CFCS**

# Participants

| Stakeholder Groups | Development Team | Nominal Group | Delphi Survey Round 1 | Delphi Survey Round 2 |
|---|---|---|---|---|
| Adults with CP | 1 (9%) | 3 (11%) | 16 (14%) | 12 (17%) |
| Educators | 1 (9%) | 4 (15%) | 8 (7%) | 5 (7%) |
| Neurologists | 1 (9%) | 1 (4%) | 5 (5%) | 5 (7%) |
| Occupational Therapists | 2 (18%) | 2 (7%) | 8 (7%) | 3 (4%) |
| Parents of Children with CP | 1 (9%) | 4 (15%) | 7 (6%) | 4 (6%) |
| Pediatricians | 2 (18%) | 3 (11%) | 13 (12%) | 8 (12%) |
| Physical Therapists | 1 (9%) | 3 (11%) | 11 (10%) | 5 (7%) |
| Speech-Language Pathologists/Researchers | 3 (27%) | 7 (26%) | 42 (38%) | 28 (41%) |
| Others | ---------- | 4 (15%) | 24 (21%) | 13 (19%) |
| **N*** | **11** | **27** | **112** | **69** |

# Comparison of Classification Tools

| | 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 |

# Forming international CP collaborations

- **Advantages**
  - Facing similar issues
  - Increase expertise
  - Access to CP population registries
    - Europe (SCPE)
    - Australia
    - Canada
  - Replicate and expand findings
  - Knowledge translation into clinical practices
- **Challenges**
  - Languages often differ
  - Culture/customs differ
  - Roles vary in different countries
  - Face-to-face communication across time zones
    - Take advantage of conferences to meet

# Current research directions

- **CFCS in cerebral palsy registries' data?**
  - Surveillance of CP in Europe (SCPE)
  - Australian Cerebral Palsy Registers (ACPR)

- **Translate/validate CFCS in languages**

- Currently underway
  - Arabic
  - Dutch
  - Turkish
  - Swedish
  - Lativian
  - Lithuanian
  - Portuguese
  - Danish

- Interests
  - Finnish
  - Norwegian
  - Brazilian Portuguese
  - Spanish
  - South African

# Current research directions

- **Measure the CFCS stability across the life span.**
  - Research partners who serve individuals with CP from age 2 to 21
    - Follow age cohorts for 4 years
    - Create a functional performance snapshot by reporting the CFCS in conjunction with GMFCS & MACS.

# Contact us

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- CFCS Website
  http://cfcs.us

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

## Purpose

The **purpose** of the CFCS is to classify the **everyday communication performance** of an individual with cerebral palsy into one of five levels. The CFCS focuses on activity and participation levels as described in the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF).

## User Instructions

A parent, caregiver, and/or a professional who is familiar with the person's communication selects the level of communication performance. Adults and adolescents with cerebral palsy may also classify their communication performance. The **overall effectiveness** of the communication performance **should be based on how they usually take part in everyday situations requiring communication,** rather than their best capacity. These everyday situations may occur in home, school, and the community.

Some communication may be difficult to classify if performance falls across more than one level. In those cases, choose the level that **most closely describes** the person's usual performance **in the most settings.** Do not consider the individual's perceived capacity, cognition, and/or motivation when selecting a level.

## Definitions

**Communication** occurs when a **sender** transmits a message ***and*** a **receiver** understands the message. An **effective communicator** independently **alternates as a sender and a receiver** regardless of the demands of a conversation, including settings (e.g., community, school, work, home), conversational partners, and topics.

**All methods of communication** performance are considered in determining the CFCS level. These include the use of speech, gestures, behaviors, eye gaze, facial expressions, and augmentative and alternative communication (**AAC**). AAC systems include (but are not limited to) manual sign, pictures, communication boards, communication books, and talking devices -- sometimes called voice output communication aids (VOCAs) or speech generating devices (SGDs).

**Distinctions between the levels** are based on the performance of **sender and receiver roles**, the **pace of communication**, and the **type of conversational partner**. The following definitions should be kept in mind when using this classification system.

**Effective senders and receivers** shift quickly and easily between transmitting and understanding messages. To clarify or repair misunderstandings, the effective sender and receiver may use or request strategies such as repeating, rephrasing, simplifying, and/or expanding the message. To speed up communication exchanges, especially when using AAC, an effective sender may appropriately decide to use less grammatically correct messages by leaving out or shortening words with familiar communication partners.

A **comfortable pace** of communication refers to how quickly and easily the person can understand and convey messages. A comfortable pace occurs with few communication breakdowns and little wait time between communication turns.

**Unfamiliar conversational partners** are strangers or acquaintances who only occasionally communicate with the person. **Familiar conversational partners** such as relatives, caregivers, and friends may be able to communicate more effectively with the person because of previous knowledge and personal experiences.

## Clarifications

- Determining the CFCS level **does not require testing**, nor does it replace standardized communication assessments. The CFCS is not a test.
- The CFCS **groups people by the effectiveness** of current communication performance. **It does not explain any underlying reasons** for the degree of effectiveness such as cognitive, motivational, physical, speech, hearing, and/or language problems.
- The CFCS **does not rate the person's potential for improvement**.
- The CFCS may be **useful in research and service delivery**, when classifying communication effectiveness is important.

  Examples include:

  **1)** describing functional communication performance using a common language among professionals and laypersons,

  **2)** recognizing the use of all effective methods of communication including AAC,

  **3)** comparing how different communication environments, partners, and/or communication tasks might affect the level chosen,

  **4)** choosing goals to improve the person's communication effectiveness.

- See page 3 for a description of the five levels.
- See page 4 for a chart to help distinguish between levels.
- Frequently-asked questions can be found on the CFCS website. http://xxxxxxxxxxxxxxxxxxx.

## Communication Methods

Regardless of the number of communication methods used, **only 1 CFCS level is assigned for the overall communication performance**. The optional box below is provided to list all the communication methods used.

The following **methods of communication** are used by this individual:
*(Please check **all** that apply)*

- ☐ Speech
- ☐ Sounds (such as an "aaaah" to get a partner's attention)
- ☐ Eye gaze, facial expressions, gesturing, and/or pointing (e.g., with a body part, stick, laser)
- ☐ Manual signs
- ☐ Communication book, boards, and/or pictures
- ☐ Voice output device or a speech-generating device
- ☐ Other

_____
_____
_____

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

**Key**
**P** Person with CP
**U** Unfamiliar Partner
**F** Familiar Partner
Effective
Less effective

**I. Effective Sender and Receiver with unfamiliar and familiar partners.**
The person independently **alternates between sender and receiver** roles with most people in most environments. The communication occurs easily and at a **comfortable pace** with both **unfamiliar and familiar conversational partners**. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

The difference between Levels I and II is the **pace** of the conversation. **In Level I**, the person communicates at a **comfortable** pace with little or no delay in order to understand, compose a message, or repair a misunderstanding. **In Level II**, the person **needs extra time** at least occasionally.

**II. Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.** The person independently **alternates between sender and receiver** roles with most people in most environments, but the **conversational pace is slow** and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstanding are often repaired and do not interfere with the eventual effectiveness of the person's communication with both **unfamiliar and familiar partners**.

The differences between Levels II and III concern **pace and the type of conversational partners**. **In Level II**, the person is an effective sender and receiver with all conversational partners, but pace is an issue. **In Level III**, the person is consistently effective with familiar conversational partners, but not with most unfamiliar partners.

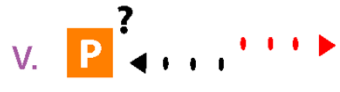
**III. Effective Sender and Receiver with familiar partners.** The person **alternates between sender <u>and</u> receiver roles with familiar** (but not unfamiliar) conversational partners in most environments. Communication is **not consistently effective** with most **unfamiliar partners**, but is **usually effective** with **familiar partners.**

The difference between Levels III and IV is **how consistently the person alternates between sender and receiver roles with familiar partners**. **In Level III**, the person is generally able to communicate with familiar partners as a sender *and* as a receiver. **In Level IV**, the person does not communicate with familiar partners consistently. This difficulty may be in sending and/or receiving.

**IV. Inconsistent Sender and/or Receiver with familiar partners.** The person does **<u>not</u>** consistently alternate **sender and receiver** roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is **sometimes effective** with **familiar partners**.

The difference between Levels IV and V is the **degree of difficulty that the person has when communicating with familiar partners**. **In Level IV**, the person has some success as an effective sender and/or an effective receiver with familiar partners. **In Level V**, the person is rarely able to communicate effectively, even with familiar partners.

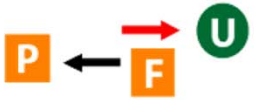
**V. Seldom Effective Sender and Receiver even with familiar partners.** The person is limited as both a **sender and a receiver**. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is **seldom effective** even with **familiar partners**.



# Current CFCS Draft

I. Effective Sender and Receiver with unfamiliar and familiar partners.

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




III. Effective Sender and Receiver with familiar partners.

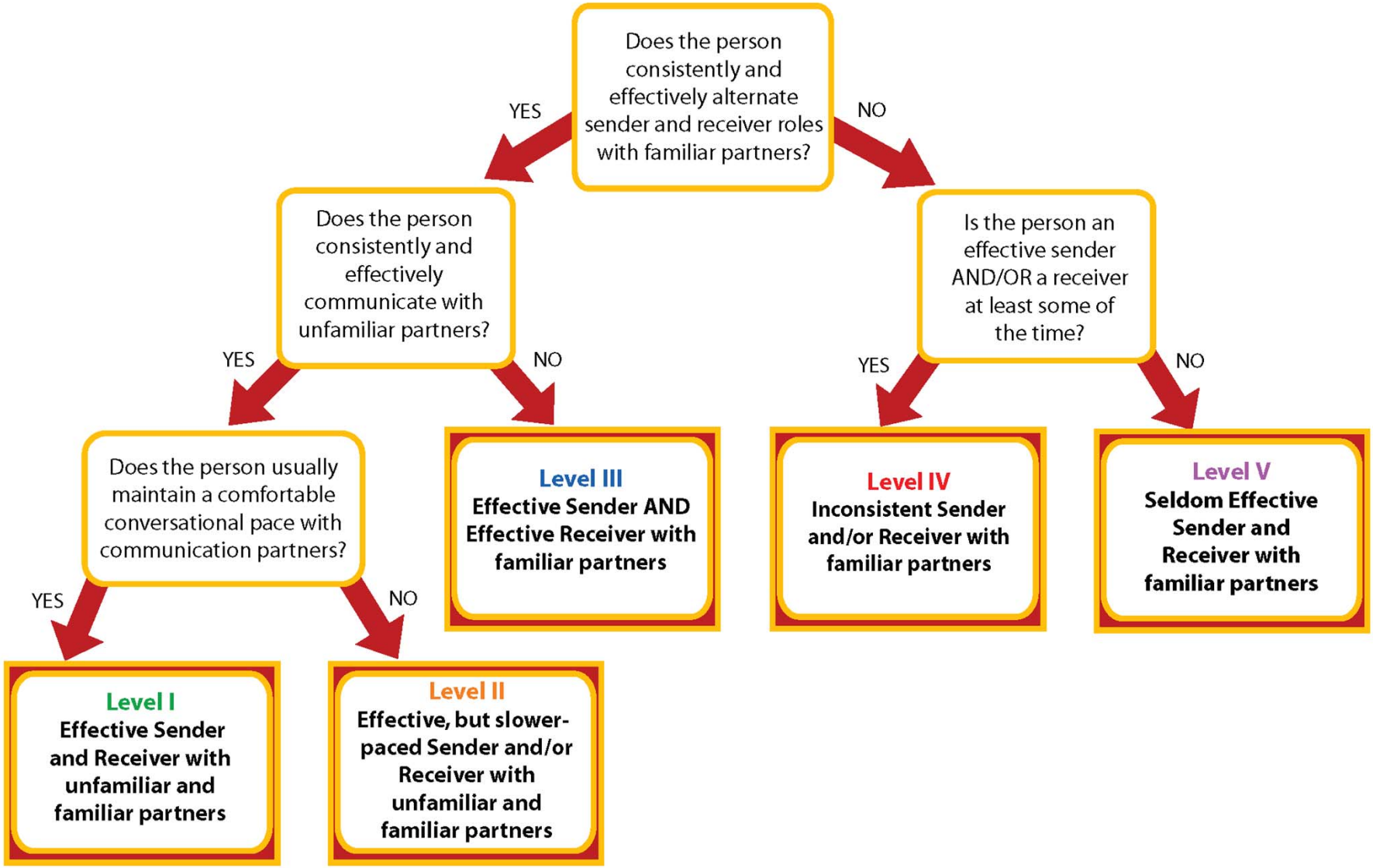
**Key**

**P** Person with CP
**U** Unfamiliar Partner
**F** Familiar Partner
Effective
Less effective

IV. Inconsistent Sender and/or Receiver with familiar partners.

V. Seldom Effective Sender and Receiver even with familiar partners.

# CFCS Level Identification Chart



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