

**Validity and reliability of the Dutch language version of the  
Communication Function Classification System (CFCS-NL)**

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## **MASTERTHESIS**

# **Validity and reliability of the Dutch language version of the Communication Function Classification System (CFCS-NL)**



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## **ABSTRACT**

### **AIM**

The Communication Function Classification System (CFCS) is currently being developed by Hidecker and colleagues to fulfil a role in the classification of communication abilities in daily life in children with cerebral palsy (CP). The CFCS for cerebral palsy aims to enhance communication among professionals and families. The aim of this study is to translate the original -American English - version of the CFCS and to evaluate the psychometric properties the Dutch language version of the CFCS.

### **METHOD and PARTICIPANTS**

Twenty two children, five in the pilot study and seventeen in the research study, in the age 4 – 10 years, diagnosed with cerebral palsy were included in this study. The parents, a teacher and a speech/physical therapist completed a survey for each child, with questions about their background, child characteristics and questions about the CFCS. Six children also got classified by two unfamiliar persons. For each child, one parent got interviewed with the PEDI-NL, social functioning domain.

### **RESULTS**

The interrater reliability between two professionals raters was found to be Kappa = 0.69. Between the parent and the speech therapist/physical therapist the kappa was 0.63 and between the parent and teacher kappa was 0.48. The interrater reliability between the unfamiliar professional and the familiar professional rater was found to be Kappa 0.75.

The correlation coefficient for the overall score on the domain social functioning and the CFCS-NL is  $r = .885$ . The correlation between the receptive items and the CFCS-NL  $r = .743$  and between the expressive items and the CFCS-NL the correlation  $r = .831$ .

### **INTERPRETATION**

This research indicates that the interrater reliability of Dutch language version of CFCS (CFCS-NL) is good. The results suggest that is important to have certain knowledge about speech and language and communication development in general when using the CFCS-NL. It therefore is recommended that the classification of a child is performed by the parents together with a therapist with certain knowledge about speech and language development. The construct validity of the CFCS-NL, in this study, seems to be good. The CFCS-NL might be useful for both clinical and research applications. The classification system makes it possible to improve communication between parents, professionals and researchers about functional communication on the level of activity and participation. Further research is necessary, especially with regards to the usability in clinical practice. Another point of attention is to extend this study with more participants.

### **KEYWORDS**

Cerebral Palsy, Child, Communication, Reliability, Validation

## **SAMENVATTING**

### **DOEL**

Op dit moment wordt het Communicatie Functie Classificatiesysteem ontwikkeld door Hidecker en collega's. Het doel van de CFCS om de dagelijkse communicatie van een kind met cerebrale parese (CP) te classificeren en daarmee de communicatie tussen professionals en ouders te optimaliseren.

Het doel van dit onderzoek is de Engelstalige CFCS te vertalen en de Nederlandstalige versie van de CFCS te onderzoeken op validiteit, betrouwbaarheid en bruikbaarheid.

### **METHODE en PARTICIPANTEN**

In totaal participeerden er tweeëntwintig kinderen met cerebrale parese, in de leeftijd van 4-10 jaar, aan het onderzoek. Vijf kinderen namen deel aan de pilotstudy, 17 kinderen participeerden in de onderzoeksstudie. Voor elk kind werd er door de ouder, leerkracht en logopedist of fysiotherapeut een vragenlijst ingevuld met betrekking tot de achtergrond van de beoordelaar, kindkenmerken en de CFCS. Zes kinderen werden daarnaast beoordeeld door twee onbekende beoordelaars. De ouders werden geïnterviewd met de PEDI-NL, domein sociaal functioneren.

### **RESULTATEN**

De inter-beoordelaars betrouwbaarheid tussen twee bekende professionals is Kappa = 0.69. Tussen de ouders en de logopedist/fysiotherapeut was de kappa 0.63 en tussen de ouder en de leerkracht de kappa was 0.48. De inter-beoordelaars betrouwbaarheid tussen de onbekende en bekende professionals was Kappa 0.75.

De correlatiecoëfficiënt tussen de totale score op het domein sociaal functioneren en de CFCS-NL is  $r = .885$ .

De correlatie tussen de receptieve items en de CFCS-NL is  $r = .743$  en bij de expressieve items en de CFCS-NL de correlatie is  $r = .831$ .

### **INTERPRETATIE**

Dit onderzoek toont aan dat de inter-beoordelaars betrouwbaarheid van de Nederlandstalige CFCS (CFCS-NL) goed is. De resultaten wijzen er op dat het belangrijk is om enige kennis te hebben over communicatie, spraak en taal, wanneer de CFCS gebruikt wordt. Er wordt dan ook aanbevolen om een kind te classificeren op basis van de gegevens van ouders en logopedist samen. De construct validiteit van de CFCS-NL in dit onderzoek is goed.

De CFCS-NL lijkt bruikbaar in zowel de klinische setting als voor onderzoeksdoeleinden en maakt het mogelijk om de communicatie tussen ouders, professionals en onderzoeker te optimaliseren wat betreft functionele communicatie op activiteiten en participatie niveau. Verder onderzoek is noodzakelijk met name naar de wijze waarop de CFCS-NL toegepast kan worden in de praktijk. Daarnaast is het belangrijk om dit onderzoek uit te breiden met meer participanten.

### **SLEUTELWOORDEN**

Cerebrale Parese, Kinderen, Communicatie, Betrouwbaarheid, Validiteit

## **BACKGROUND**

### **The definition, prevalence and diagnosis of cerebral palsy**

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems. 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. 2006).

In The Netherlands the prevalence of cerebral palsy is approximately 2 cases per 1000 live births with a male – female ratio of 61 – 39% (Wichers, Odding, Stam & Van Nieuwenhuizen, 2005). These numbers are in line with the prevalence of CP in the Western part of Europe (SCPE, 2002).

Subgroups of cerebral palsy have been mainly classified according to their predominant type of neuromotor abnormality (spastic, dyskinetic or ataxic CP) and affected limbs (unilateral involvement (hemiplegia), or bilateral involvement (diplegia and quadriplegia) (Gorter, 2004 & Rosenbaum et.al., 2006)(see figure 1 for the definition from the SCPE: Surveillance of Cerebral Palsy in Europe). However, these descriptions do not provide information about the functional abilities of a child in daily live. The WHO International Classification of Functioning, Disability and Health (ICF) emphasizes the importance of evaluating the functional consequences of different health states by using objective

functional classifications scales. Recent developed classification systems focusing on functional abilities are the Gross Motor Function Classification System (GMFCS; Palisano et.al., 1997) and the Manual Ability Classification System (MACS; Eliasson, Krumlinde-Sundholm & Rösblad, 2006).

Another functional classification system is currently being developed, the Communication Function Classification System (Hidecker et.al., 2009). The purpose of the CFCS is to classify the everyday communication performance of an individual with cerebral palsy into one of five levels. Figure 2 shows the three functional classification systems en their levels.

### **The use of a classification system**

The general diagnosis of cerebral palsy covers a broad range of clinical presentations and degrees of activity limitation (Rosenbaum et.al., 2006). It is useful to further categorize children with CP into classes or groups. Rosenbaum and colleagues point out that these classification systems should include: (1) Description of the problem and its severity; (2) Prediction that gives information about the current and future needs of individuals with CP; (3) The ability to compare series of cases of CP; (4) The possibility to allow comparison of the same individual with CP at different points in time. Another challenge when developing a classification system is that it has to be understandable to all persons interested in CP, not only for professionals but also for parents. Eliasson et.al. (2006) also states that the usefulness of a classification system depends on how understandable and clear the descriptions of the classification system are, and how discriminative different levels are.

The Communication Function Classification System as well as the other functional classification systems make a distinction between the capacity of a person and their performance. Capacity refers to what an individual can do (activity) and performance refers to what an individual actually does (participation). These qualifiers are also a part of the ICF.

The ICF-model (figure 3) is an integrated model of both medical and social models. The model provides a coherent view of different perspectives of health: biological, individual and social. Disability and functioning are seen as outcomes of interaction between health conditions and contextual factors. Contextual factors can be divided into external environmental factors (for example, social attitudes, legal structures, climate) and internal personal factors (for example age, gender, social background).

In the process of developing a classification system for functional communication the contextual factors are very important to consider. For example language development is closely related to social background. A lower social background can have influence on the performance of an individual with CP. The availability of Augmentative and Alternative Communication (AAC) – devices is also related to activity and participation of an individual with cerebral palsy. The CFCS focuses on activities and participation and it aims to show that the underlying problems in body functions and structure do not predict participation in daily life.



## **Functional communication**

Functional communication is defined by the American Speech Language Hearing Association as the ability to receive or convey a message, regardless of the mode, to communicate effectively and independently in a given environment. According to the WHO-ICF communication concerns the transmitting and receiving of messages in different environments using multiple means of communication including listening, speaking, reading and writing. Communication also concerns conversation and the use of communication aids en techniques.

Communication occurs when a sender transmits a message and its receiver understands the message. An effective communicator independently alternates as both between the role of sender and receiver. This role is regardless of the demands of the conversation, settings, conversational partners and topics. Communication relies on the underlying speech, language and hearing skills of individuals and people with severe disabilities may benefit from the use of assistive technology as augmentative and alternative communication (AAC) and hearing aids (Haak, Lenski, Hidecker, Li, & Paneth, 2009).

Children with cerebral palsy can experience problems in the acquisition of receptive and expressive language, voice production, speech, facial expression and in the ability to develop reliable gesture (Pennington, Goldbart & Marshall, 2009). These restrictions in combination with their motor impairment en co-morbidities, such as cognitive, visual and hearing impairments are likely to have a negative effect on their ability to communicate.

Communication limitations can be associated with any type of cerebral palsy.

According to a MRI-study performed by Bax, Tydeman & Flodman (2006) communication problems occur in 58% of the children with cerebral palsy, with the highest percentage in children with a dyskinetic type or bilateral spastic type (quadriplegia) of CP and lowest in

children with a spastic type with bilateral (diplegia) or unilateral (hemiplegia) involvement.

Voorman, Dalmeijer, Van Eck, Schuengel & Becher (2009) studied the social functioning and communication in children with CP and found that 74% of the children with CP had restrictions in communication (GMFCS level I 58%, GMFCS level II 81%, GMFCS level III and IV 85% and GMFCS level V 100%). Kuroda & Durkin (2001) performed a population based estimate of communication disorders among persons with cerebral palsy in the United States of America. They categorized communication deficits into three groups: (1) mild, difficulty communication so that non-family members understand, (2) moderate, difficulty communicating so that family members, (3) severe, difficulty communicating basic needs to family members. They report that 17% of individuals with CP had communication problems and the individuals with CP and co morbidities had communication problems in up to 48% percent. The receptive communication was disturbed in 15% of the cases, 26% experienced difficulty with expressive communication. Although many studies described the prevalence of communication disorders in children en adults with CP there is no consistent method of classifying communication.

## **COMMUNICATION FUNCTION CLASSIFICATION SYSTEM (CFCS)**

The CFCS is developed in the past few years by Hidecker and colleagues (Hidecker et.al. 2008) and is an ordinal system that is modelled on the GMFCS and MACS. The goal of this classification system is to classify everyday communication performance in children with cerebral palsy into one of five descriptive levels. Distinctions between the five levels are based on important aspects of function communication: 1) the performance of sender and receiver roles, 2) pace of the conversation, 3) type of conversational partner. The classification must be based on the overall effectiveness of the communication performance. All methods of communication are considered in determining the CFCS level, see figure 4 for an overview of methods of communication. The CFCS research group also developed a decision-making algorithm; this algorithm was not only a helping tool in the developmental process of the CFCS but is also helps people to make classification decisions (Rosenbaum, Palisano, Bartlett, Galuppi, Russell, 2008).

### **Important aspects of the CFCS**

#### ***Sender and receiver roles***

The CFCS gives the following definition of effective sender and receivers:

*“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.”*

Beukelman & Mirenda (2005) underwrite this definition and state that the an effective sender and receiver is also able to 1) show interest in others an draw others into interactions, 2) actively participate and take turns in a symmetrical fashion, 3) are responsive to their communication partners.

The CFCS is based on the assumption that in order to be an effective communication person an individual has to be both an efficient sender and receiver. This makes it possible that a person with a severe movement disorder with normal language comprehension skills is classified as an inconsistent or ineffective sender and/or receiver.

### ***Conversational pace***

Another important aspect of functional communication is the conversational pace. The CFCS gives the following definition of comfortable conversational pace:

*“A comfortable pace of conversation refers to how quickly and easily a person can understand and convey messages. A comfortable pace occurs with few communication breakdowns and little wait time between communication times.”*

The conversational speaking rates of natural speakers without disabilities vary from 150 words per minute to 250 words per minute (Goldman-Eisler, 1986, as cited in Beukelman & Mirenda, 2005). These rates make efficient communication possible. The content and meaning of a message can be derived from the context and timing of the message. Some individuals with CP experience restriction in their communication interaction because of their limited conversational rate. When the conversational pace is affected it may be impossible to make a quick comment during a situation that requires a quick response (greeting in the hallway, during a game).

Conversational pace can be a problem in children with dysarthric speech and other speech and language disorders but is especially of influence in children that use AAC to

communicate. There are studies that report that AAC users communicate with less than 15 words per minute under most circumstances (Foulds, 1987, as cited in Beukelman & Mirenda, 2005).

### ***Conversational partners***

The CFCS distinguishes conversational partners into familiar and unfamiliar conversational partners.

*“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 with the person because of previous knowledge and experience.”*

The distinction between familiar and unfamiliar conversational partners is also shown in the Circles of Communication Partners (CCP) (figure 5).

Individuals with CP will experience different social relationships and interact in many different people in many different environments. Of course this will influence communication and its effectiveness.

## **DUTCH VERSION COMMUNICATION FUNCTION CLASSIFICATION SYSTEM (CFCS-NL)**

Because of the importance of clear and discriminative level descriptions, as mentioned before, it is very important to test the reliability and validity of the Dutch translation of the Communication Function Classification System. Cultural and social differences can be of influence on the validity and reliability of an instrument. Until now, the CFCS has been used only in the United State of America and mainly by the developers of the CFCS. There is still little information about the CFCS in international publications.

The aim of this study is to translate and psychometric evaluate the Dutch language version of the CFCS.

The following research questions have been formulated:

1. What is the reliability of the Dutch CFCS in children with CP children at the age 4 - 10?
2. How does the Dutch CFCS in children with CP relate to other indicators of communication and social interaction?
3. What is the usability of the Dutch CFCS?

### **Translation**

The original CFCS is translated into Dutch according to the procedure described by Guillemin et al. (1993). Briefly this procedure involves (1) forward translation of the English CFCS into Dutch by a native Dutch speaker with fluency in English; (2) backward translation of the provisional Dutch translation into American-English by a native speaker English with fluency in Dutch.

The first concept translation has been discussed in a group of experienced speech and language therapists, all working in the field of rehabilitation. This expert group, five speech and language therapists, a pediatric psychiatrist and a pediatric neurologist, reviewed the first draft both on the content as well as the readability of the translation.

After this extra step in the translation process, the backward translation was performed and there was a very good agreement with the original version. The result of the translation was then discussed with the developers of the CFCS and they approved the final version as research version for this study (appendix 1).

After the translation process we performed a small pilot study in the VU University Medical Centre. In this small experiment we asked only professionals to classify five children, all diagnosed with Cerebral Palsy, with the CFCS-NL. The absolute agreement between professionals in this pilot study was low and there was a lot of discussion about the classification levels. Because of the possibility that the poor agreement in this pilot study is the result of using only professionals whom are not familiar conversational partners from the child and these professionals have little knowledge about the communication of the child (neurologists, paediatrics, etc), this study proposal includes raters who are familiar with the child and its daily functional communication and two unfamiliar raters with specific knowledge about communication and cerebral palsy.

## **Methods**

### ***Participants***

A total of twenty two children was available for this study. Three participants got excluded because they did not meet the inclusion criteria (not diagnosed with cerebral palsy) or not all three familiar raters filled out the questionnaire.

This study is based on a convenience sample of seventeen children, 10 boys and 7 girls, between 4 – 10 years of age. All participants were diagnosed with cerebral palsy, 12 children had been diagnosed with cerebral palsy of the spastic subtype, 2 children had been diagnosed with the dyskinetic subtype, two children with the ataxic subtypes and 1 child was diagnosed with a mixed cerebral palsy. The children were recruited from a rehabilitation setting or a specialized day care. Participant characteristics are shown in figure 6.

Parents of all participants gave written informed consent for their child to be included in the study. All raters signed an informed consent as well.

### ***Procedure and instruments***

The parents, teacher and speech therapist or physical therapist of each child were asked to fill out a questionnaire (appendix B). This survey contains questions about the background of the rater, the background en medical conditions of the child and questions about the CFCS-NL classification system.

Six children also got classified by two unfamiliar persons, a speech therapist with more than five years of experience and a speech therapist with less than one year experience.



The unfamiliar raters based their classification of video sample of the child with CP in the home situation. In that situation the child talked to a familiar person, in most cases the parent, and an unfamiliar person, the researcher.

The familiar conversational partners were asked to base their classification on how the child usually takes part in everyday situations requiring communication.

One parent of each child was interviewed with the Dutch language version of the Pediatric Evaluation of Disability Inventory (PEDI-NL, Haley ). This is a judgment based structured interview for parent of disabled children. For this study only the social functioning domain of the PEDI-NL got administered. The PEDI-NL was used in this study because there is no golden standard to examine the functional communication of a person with cerebral palsy. Most standardized test and observational instruments are not developed to examine functional communication. They exclusively assess language comprehension or expressive language. In addition, most language and communication instruments are developed for typically developing children.

### ***Statistical analysis***

For the statistical analyses all data from the questionnaires and from the PEDI-NL are imported in SPSS 17.

The interrater reliability was analysed with the use of Cohen's Kappa to determine consistency among pairs of raters. Kappa statistics were considered as poor agreement when lower than 0.20, as fair between 0.21 and 0.4, as moderate between 0.41 and 0.6, as good between 0.61 and 0.8 and as very good between 0.81 and 1.0 (Cohen, 1960).

The validity of the CFCS-NL is measured with the Pearson product-moment correlation. For the interpretation of these results we use the definition of the Dutch COTAN

commission (Evers, 2004): poor  $r$  is lower than .70, adequate  $r$  is between 0.7 and 0.8 and good when  $r$  is between 0.81 and 1.0.

## **Results**

### ***Interrater reliability***

The familiar raters agreed on the CFCS level for 8 children (47%) and disagreed by one level for 8 children (47%). Of these disagreements, 2 were between the levels I and II, 3 were between the levels II and III, 1 was between the levels III and IV, and 2 were between levels IV and V. In one case the parents classified their child with CFCS level IV and the professionals classified the child as a CFCS level I.

The interrater reliability between two professional raters was found to be Kappa = 0.69 (see figure 7a). The interrater reliability between the parent and the speech therapist/physical therapist was kappa 0.63 (see figure 7b) and between the parent and teacher kappa was 0.48 (see figure 7c).

For the 6 children that were observed by the two unfamiliar raters, the unfamiliar raters agreed in the CFCS level for 4 children (67%) and disagreed by one level for two children (33%) (see figure 8a). The interrater reliability between the unfamiliar professional with >5 years experience and the familiar professional rater was found to be Kappa 0.75 (see figure 8b) and between the unfamiliar professional with less than 1 year experience and the familiar professional kappa was found to be Kappa 0.75 as well (see figure 8c).

In a total of 63 classifications observers indicate to be sure about their classification in 40 classifications (63 %), in 18 cases (29%) the raters are reasonably sure and in 5 cases (8%) the rater was not sure of the level of classification.

### ***Construct validity***

The Pearson product-moment correlation was calculated to estimate the concurrent validity between the CFCS-NL and the PEDI-NL. For this purpose the total functional skill scores on the social functioning domain have been calculated as well as scores on the receptive items and expressive items of the PEDI-NL.

The correlation coefficient for the overall score on the domain social functioning and the CFCS-NL is  $r = .885$ . The correlation between the receptive items and the CFCS-NL  $r = .743$  and between the expressive items and the CFCS-NL the correlation  $r = .831$ .

### **Discussion**

This research indicates that the interrater reliability of Dutch language version of CFCS (CFCS-NL) is good. The interrater reliability between the parent and the teacher is moderate, but the reliability between the parents en the therapist as well as between two professionals is found to be good. Unfamiliar speech and language pathologists show a good interrater reliability with the familiar therapist.

These results suggest that is important to have certain knowledge about speech and language en communication development in general when using the CFCS-NL. It therefore is recommended the classification of a child is performed by the parents together with a therapist with interest in and knowledge about speech and language development. The parent is the expert on how the child communicates in daily functioning and a speech and language therapist is specialized in functional communication.

The validity of the CFCS-NL is good in general when associated with the PEDI-NL. The association between the total score on the social function domain and the CFCS-NL is higher than on the receptive and expressive items. This can be explained by the fact that communication is a much more broad and complex activity than just the ability to understand or produce speech and language.

As mentioned before the PEDI-NL, social scale, is not a perfect golden standard. It is developed to investigate social functioning, not communication. Although they overlap there is also a great difference between these two domains and this should be taken into account when looking to the results.

The preliminary results from the interrater reliability study on the original version of the CFCS (Hidecker et.al., 2010) show a high resemblance with the results of this Dutch study. Communication is a complex phenomenon but the CFCS seems to be capable to classify on the essential topics related to communication.

This study also has some limitations that must be considered in interpreting the results. The results are based on a convenience sample of children with cerebral palsy. Subgroups are not equally distributed according to GMFCS or type of cerebral palsy. Another limitation of this study is the small number of participants.

The CFCS-NL may be useful for both clinical and research applications. The classification system makes it possible to improve communication between parents, professionals and researchers about functional communication on the level of activity and participation.

In combination with the GMFCS and the MACS it is possible to create an overall picture of the daily functional performance of a child with cerebral palsy.

Future research should focus on how reliable the CFCS-NL is in other age groups. Other studies have shown that classification systems are less reliable in young children (below four years and especially children under the age of two year). It would be interesting to see how reliable the CFCS is within this age group. It is strongly advisable to develop a test for functional communication and make it possible to investigate communication on participation level.

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Special thanks to all children, parents, teachers and other professionals that participated in this study.

## FIGURES AND TABLES

Figure 1: SCPE Classification for cerebral palsy, based on clinical features

**Spastic Cerebral Palsy** is characterised by **at least two** of:

- Abnormal pattern of posture and/or movement
- Increased tone (not necessarily constantly)
- Pathological reflexes (hyper-reflexia or pyramidal signs e.g. Babinski response)
- It may be unilateral (hemiplegia) or bilateral

**Ataxic Cerebral Palsy** is characterised by **both** of

- Abnormal pattern of posture and/or movement
- Loss of orderly muscular co-ordination, so that movements are performed with abnormal force, rhythm and accuracy

**Dyskinetic Cerebral Palsy** is characterised by **both** of

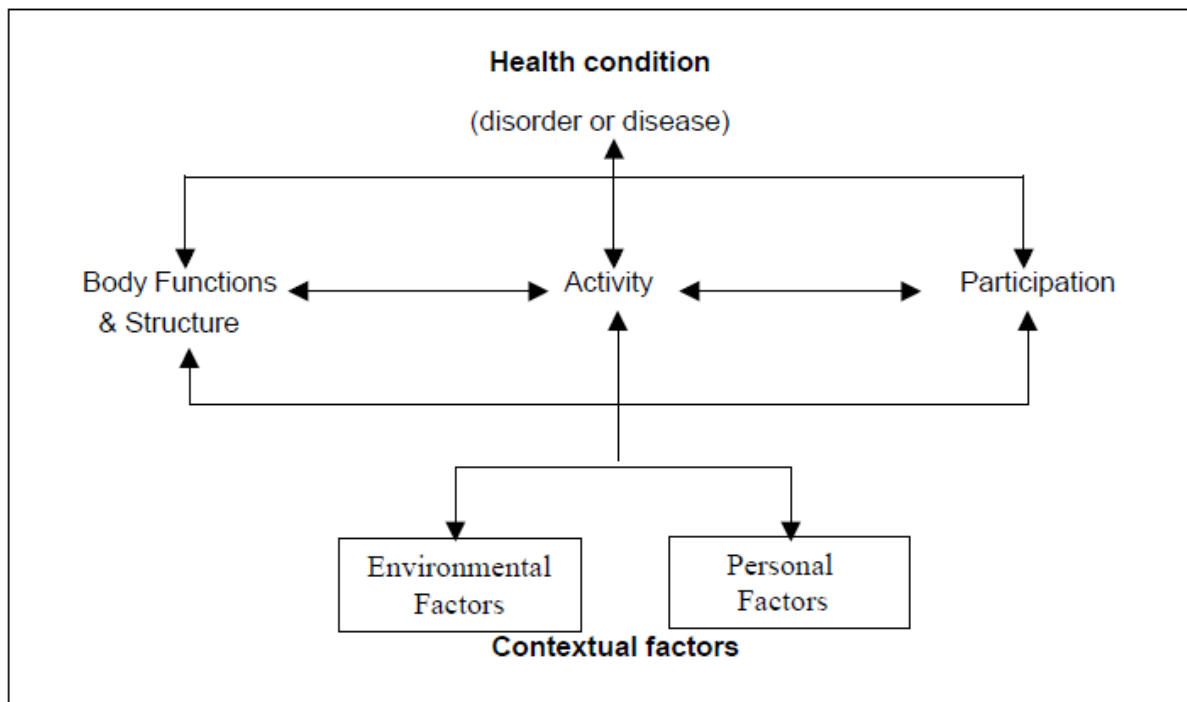
- Abnormal pattern of posture and/or movement
- Involuntary, uncontrolled, recurring, occasionally stereotyped movements of affected body parts
- Dyskinetic Cerebral Palsy may be either
  - **Dystonic** Cerebral Palsy, dominated by both hypokinesia and hypertonia.
  - **Choreo-athetotic** Cerebral Palsy, dominated by both hyperkinesia and hypotonia

**Figure 2: The levels of the GMFCS, MACS and CFCS (Hidecker et.al., 2009)**

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



**Figure 3: The ICF-model and the formal description of the components**



**Body Functions** are physiological functions of body systems (including psychological functions).

**Body Structures** are anatomical parts of the body such as organs, limbs and their components.

**Impairments** are problems in body function or structure such as a significant deviation or loss.

**Activity** is the execution of a task or action by an individual.

**Participation** is involvement in a life situation.

**Activity Limitations** are difficulties an individual may have in executing activities.

**Participation Restrictions** are problems an individual may experience in involvement in life situations.

**Environmental Factors** make up the physical, social and attitudinal environment in which people live and conduct their lives..

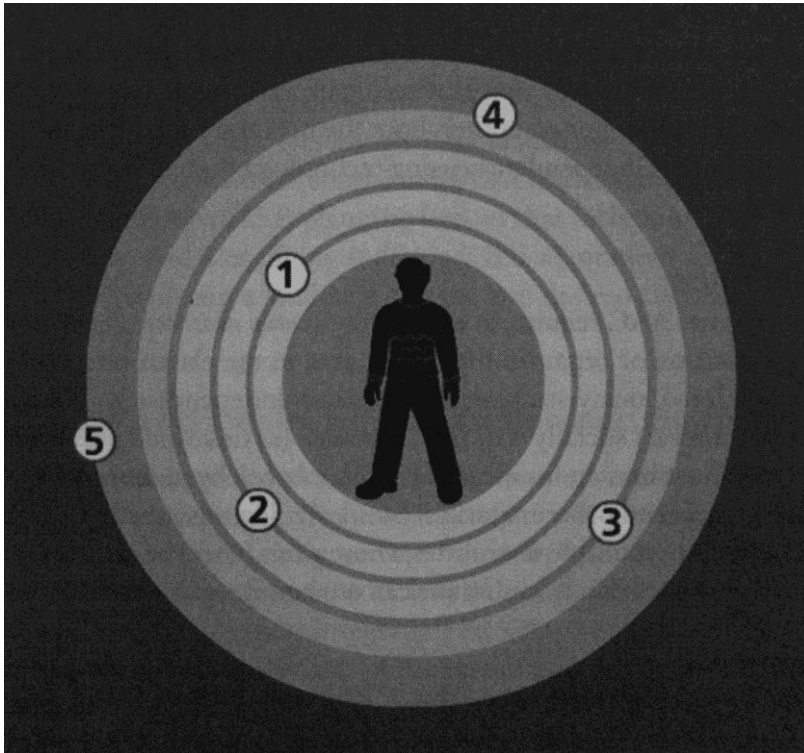
**Figure 4: Methods of communication**

This list is based on the overview by Heim, Jonker & Veen (2009).

Facial expression	Expressing feelings by facial expression (joy, sadness, pain, anger); in this case nearly always the communicative signals indicate a person feelings and are not used symbolically.
Bodily movement/action	The use of body movement or targeted bodily action in a contextual relation to communication (for example: reaching out to an object, pushing away an offered object, hitting or patting, averting, showing an object by reaching out an arm, tapping or beating an object to draw attention or as an expression of protest, handing over an object, seizing some one's hand to get something done.
Viewing direction	Visual focus on a person, an object or an location in a contextual relation to communication (using eyes to point something out); symbolic use of viewing direction, for example [yes] and [no].
Pointing	Pointing at a person, object or location using finger(s), hand, foot.
Learned gestures	The use of cultural gestures or pantomime for communicative purposes (reach out with opened palm of the hand, wave, beckon, shake one's head, nodding); the use of gestures from a gesture language system; personal gestures, that are consistently, to refer to something.
Vocalization	The use of unintelligible speech or meaningless vocalization.
Sound	Drawing the attention by use of a sound producing device in a communicative context (for example a horn).
Speech using own vocals	The use of intelligible speech or attempting to.
Speech using speech generating device	The use speech through means of a voice output communication aid.
Referrers	The use of (miniature)objects to refer to something.
Photo's	The use of photo's that refer to persons, objects or activities.
Pictures/drawings	The use of pictures/drawings that refer to persons, objects or activities.
Graphic symbols	The use of a graphic symbol system (for example PCS, Bliss)
Writing (signs)	The use of letter, numbers or written language.

**Figure 5: Circles of Communication Partners (CCP)**

- 1) Life partners
- 2) Close friends/relatives
- 3) Acquaintances
- 4) Paid workers
- 5) Unfamiliar communication Partners



From Blackston S. & Hunt Berg M. (2003) *Social networks: a communication inventory for individuals with complex needs and their communication partners – Inventory booklet* (p.30) Monterey, CA: Augmentative Communication. Adapted from Beukelman & Mirenda (2005).

**Figure 6: Participant characteristics**

	<i>n</i>
<b>Patients</b>	17
<b>Mean age (months)</b>	88
<b>Gender:</b>	
Male	10
Female	7
<b>Cerebral palsy type:</b>	
Spastic	12
Ataxic	2
Dyskinetic	2
Mixed	1
<b>GMFCS:</b>	
Level I	0
Level II	6
Level III	1
Level IV	4
Level V	6
<b>MACS:</b>	
Level I	4
Level II	3
Level III	4
Level IV	4
Level V	2

## Figure 7: Interrater reliability familiar persons

Figure 7a. Professional 1 / Professional 2

		Familiar professional 2 (Speech therapist / physical therapist)					Total
		CFCS level 1	CFCS level 2	CFCS level 3	CFCS level 4	CFCS level 5	
Familiar professional 1 (teacher)	CFCS level 1	3	1	0	0	0	4
	CFCS level 2	1	0	0	0	0	1
	CFCS level 3	0	0	4	0	0	4
	CFCS level 4	0	0	0	2	1	3
	CFCS level 5	0	0	0	1	4	5
Total		4	1	4	3	5	17

Figure 7b. Parent / Professional 2

		familiar professional 2 (Speech therapist / physical therapist)					Total
		CFCS level 1	CFCS level 2	CFCS level 3	CFCS level 4	CFCS level 5	
Parent	CFCS level 1	3	0	0	0	0	3
	CFCS level 2	0	1	2	0	0	3
	CFCS level 3	0	0	1	0	0	1
	CFCS level 4	1	0	1	3	1	6
	CFCS level 5	0	0	0	0	4	4
Total		4	1	4	3	5	17

Figure 7c. Parent / Professional 1

		Familiar professional 1(teacher)					Total
		CFCS level 1	CFCS level 2	CFCS level 3	CFCS level 4	CFCS level 5	
Parent	CFCS level 1	2	1	0	0	0	3
	CFCS level 2	1	0	2	0	0	3
	CFCS level 3	0	0	1	0	0	1
	CFCS level 4	1	0	1	3	1	6
	CFCS level 5	0	0	0	0	4	4
Total		4	1	4	3	5	17

**Figure 8: Interrater reliability unfamiliar persons**

Figure 8a. Unfamiliar 1 / unfamiliar 2

		Unfamiliar 1			Total
		CFCS level 1	CFCS level 2	CFCS level 5	
Unfamiliar 2	CFCS level 1	2	1	0	3
	CFCS level 2	0	1	0	1
	CFCS level 5	0	0	2	2
Total		2	2	2	6

Figure 8b. Unfamiliar professional 1 (with > 5 years experience) / familiar professional

		Unfamiliar professional 1			Total
		CFCS level 1	CFCS level 2	CFCS level 5	
Familiar professional 2 (Speech therapist / physical therapist)	CFCS level 1	2	1	0	3
	CFCS level 2	0	1	0	1
	CFCS level 5	0	0	2	2
Total		2	2	2	6

Figure 8c. Unfamiliar professional 2 (with <1 year experience) / familiar professional

		Unfamiliar professional 2				Total
		CFCS level 1	CFCS level 2	CFCS level 4	CFCS level 5	
Familiar professional 2 (Speech therapist / physical therapist)	CFCS level 1	2	1	0	0	3
	CFCS level 2	1	0	0	0	1
	CFCS level 5	0	0	1	1	2
Total		3	1	1	1	6

## APPENDIX A

### COMMUNICATIE FUNCTIE CLASSIFICATIE SYSTEEM (CFCS) VOOR KINDEREN, JONGEREN EN VOLWASSENEN MET EEN CEREBRALE PARESE

COMMUNICATION FUNCTION CLASSIFICATION SYSTEM

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NEDERLANDSE VERTALING:

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#### Doel:

Het **doel** van de CFCS is het classificeren van **de dagelijkse communicatie** van een persoon met cerebrale parese. De persoon wordt in een van de vijf niveaus ingedeeld. De CFCS richt zich op het niveau van “activiteiten en participatie”, zoals deze beschreven is in de International Classification of Functioning, Disability and Health (ICF) van de Wereldgezondheidsorganisatie (WHO).

#### Gebruikersinstructie:

Een ouder, verzorger en/of professional die de persoon en zijn/haar communicatieve mogelijkheden kent, stelt het functionele communicatieniveau vast. Volwassenen en jongeren met cerebrale parese kunnen wellicht ook zelf hun communicatieve mogelijkheden classificeren.

Bij het classificeren gaat het niet om het vaststellen van het optimale communicatieve vermogen (capaciteit) van de persoon, maar om hoe de persoon normaliter **effectief** participeert in de dagelijkse **situaties waarin communicatie plaatsvindt** (uitvoering). Deze situaties betreffen de communicatie thuis, op school en in de samenleving.

Sommige personen zijn wellicht moeilijk te classificeren omdat hun vaardigheden in meerdere niveaus passen. In dat geval wordt er gekozen voor het niveau dat het **meest overeenkomt** met het communicatief functioneren van de persoon in de **meeste situaties**. Daarbij wordt geen rekening gehouden met cognitieve mogelijkheden en/of motivatie.

#### Definities:

Communicatie houdt in dat een **zender** een boodschap overbrengt **én** de ontvanger de boodschap begrijpt. Een **effectief communicerend persoon** wisselt zelfstandig de rol van zender en ontvanger af, ongeacht de eisen aan de conversatie. Hierbij kan er sprake zijn van verschillende communicatieve situaties (school, werk, thuis, etc.), verschillende communicatiepartners en verschillende onderwerpen.

**Alle manieren van communiceren** worden meegerekend bij het vaststellen van het CFCS-niveau. Zowel het gebruik van spraak als ondersteunende communicatievormen (o.a. gedrag, gebaren, mimiek) wordt meegerekend. Ondersteunende communicatievormen en –middelen bestaan o.a. uit gebarentaal, afbeeldingen/foto's, communicatiekaarten, communicatieboeken en communicatieapparatuur met spraakuitvoer.

Het **onderscheid tussen de verschillende niveaus** wordt gemaakt op basis van de vaardigheid in het **zenden en ontvangen** van een boodschap, de **conversatiesnelheid** en het **soort communicatiepartner**.

Aandachtspunten bij het classificatiesysteem zijn:

**Effectieve zenders en ontvangers** wisselen snel en gemakkelijk tussen het zenden en ontvangen van boodschappen. Om de boodschap te verhelderen en misverstanden op te lossen worden strategieën gebruikt zoals herhaling, herstructurering, vereenvoudiging en uitbreiding van de boodschap. Om de conversatiesnelheid op peil te houden kan de zender (m.n. de OC-gebruiker) er bij bekende

communicatiepartners voor kiezen grammaticaal minder correcte zinnen te gebruiken, door woorden weg te laten of in te korten.

Een **comfortabele conversatiesnelheid** heeft betrekking op de snelheid en het gemak waarmee een persoon de boodschap begrijpt en overbrengt. Bij een normale conversatiesnelheid zijn er slechts enkele natuurlijke stiltes en korte pauzes bij beurtwisselingen.

**Onbekende communicatiepartners** zijn onbekenden en kennissen die slechts een enkele keer met de persoon communiceren. **Bekende communicatiepartners** zoals familie, zorgverleners en vrienden zijn mogelijk in staat meer effectief met de persoon te communiceren door eerdere ervaringen en reeds opgedane kennis.

#### Verduidelijkingen

- De CFCS is geen test en het vaststellen van het CFCS-niveau **vereist geen testafname**. De CFCS is geen vervanging van gestandaardiseerd communicatieonderzoek.
- De CFCS **groepeert personen op basis van hun huidige effectieve communicatiegebruik**. Het instrument verklaart niet welke oorzaken er ten grondslag liggen aan het niveau van effectiviteit zoals cognitie en motivatie, motorische problemen en gehoor-, spraak-, en/of taalproblemen.
- De CFCS doet **geen uitspraak over de mogelijkheid tot vooruitgang**.
- De CFCS **kan bruikbaar zijn bij onderzoek en hulpverlening** wanneer het classificeren of groeperen van de functionele communicatie gewenst is. Voorbeelden hiervan zijn:
  - 1) Het op uniforme wijze beschrijven van de functionele communicatie van een persoon door professionals en leken.
  - 2) Het onderkennen van het gebruik van alle mogelijke (ondersteunende) communicatievormen, inclusief communicatiehulpmiddelen.
  - 3) Het vergelijken van de invloed van communicatieve mogelijkheden in verschillende communicatieve situaties, met diverse communicatiepartners en/of communicatieve taken op het gekozen niveau.
  - 4) Het vaststellen van doelen om de effectieve communicatie van een persoon te verbeteren.

- Zie pagina 3 voor een beschrijving van de vijf niveaus.
- Zie pagina 4 voor een grafiek ter ondersteuning van het onderscheiden van de niveaus.
- Veelgestelde vragen zijn te bekijken op de website. <http://www.....>

#### Communicatievormen/middelen

Ongeacht het aantal communicatievormen dat de persoon gebruikt, wordt er slechts één CFCS-niveau vastgesteld voor het gehele communicatiegebruik. Het onderstaande overzicht kan gebruikt worden om het communicatiesysteem van een persoon vast te leggen.

De persoon maakt gebruik van het volgende communicatiesysteem (kruis alle mogelijkheden die van toepassing zijn aan):

- Spraak
- Geluiden (bijvoorbeeld “aaaaah” om iemand zijn aandacht te trekken)
- Lichaamstaal, gedrag, kijken, mimiek, gebaren en/of wijzen
- Gebaren (ondersteunde gebaren of gebarentaal)
- Communicatieboek, aanwijskaarten/bladen en/of afbeeldingen (foto's, pictogrammen)
- Communicatieapparaat (met spraakuitvoer)
- Anders, nl.



Verklaring van de gebruikte symbolen:	
<b>P</b>	Persoon met Cerebrale Parese
<b>B</b>	Bekende personen
<b>O</b>	Onbekende personen
<b>—</b>	Effectief
<b>.....</b>	Minder effectief

I. Effectieve zender en ontvanger met zowel bekende als onbekende communicatiepartners.

De persoon **wisselt zelfstandig de rol van zender en ontvanger** met de meeste mensen in de meeste situaties. De communicatie verloopt probleemloos met zowel **bekende als onbekende communicatiepartners** op een **comfortabele conversatiesnelheid**. Misverstanden in de communicatie worden snel opgelost en verstoren niet de algehele effectieve communicatie van de persoon.

II. Effectieve maar vertraagde zender en/of ontvanger met bekende en onbekende communicatiepartners.

De persoon **wisselt zelfstandig de rol van zender en ontvanger** met de meeste mensen in de meeste situaties, maar de **conversatiesnelheid is vertraagd** en kan de interactie bemoeilijken. De persoon heeft mogelijk meer tijd nodig om ontvangen boodschappen te begrijpen, een boodschap te formuleren en/of misverstanden op te lossen. De misverstanden in de communicatie worden vaak opgelost en verstoren niet de algehele effectieve communicatie van de persoon met **bekenden en onbekenden**.

III. Effectieve zender en ontvanger met bekende communicatiepartners.

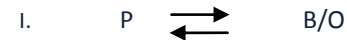
De persoon wisselt in de meeste situaties **de rol van zender en ontvanger met bekende personen** (maar niet met onbekenden). Communicatie is **niet altijd succesvol met onbekenden**, maar **meestal wel met bekende communicatiepartners**.

IV. Wisselend effectieve zender en/of ontvanger met bekende communicatiepartners.

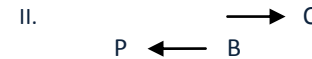
De persoon **wisselt niet consequent de rol van zender en ontvanger**. Deze inconsequentie kan zich uiten in: a) af en toe een effectieve zender en ontvanger zijn b) een effectieve zender maar beperkte ontvanger zijn c) een beperkte zender maar effectieve ontvanger zijn. Communicatie is **soms succesvol met bekende communicatiepartners**.

V. Zelden effectieve zender en ontvanger zelfs met bekende communicatiepartners

De persoon is beperkt **zowel als zender als ontvanger**. De communicatie van de persoon is voor de meeste mensen moeilijk te begrijpen. De persoon is beperkt in het begrijpen van boodschappen. Communicatie is **zelden effectief**, zelfs met **bekende communicatiepartners**.



Het verschil tussen niveau I en II is de **conversatiesnelheid**. Op **niveau I** communiceert de persoon op een **comfortabele** snelheid met nauwelijks tot geen vertraging in het begrijpen of formuleren van een boodschap en in het oplossen van misverstanden. Op **niveau II** heeft hij/zij hiervoor, in sommige gevallen, **extra tijd** nodig.



De verschillen tussen niveau II en III zijn de **conversatiesnelheid en het soort communicatiepartners**. Op **niveau II** communiceert de persoon effectief met zowel bekende als onbekende communicatiepartners en alleen de conversatiesnelheid is opvallend. Op **niveau III** communiceert de persoon effectief met bekende communicatiepartners maar niet met onbekenden.

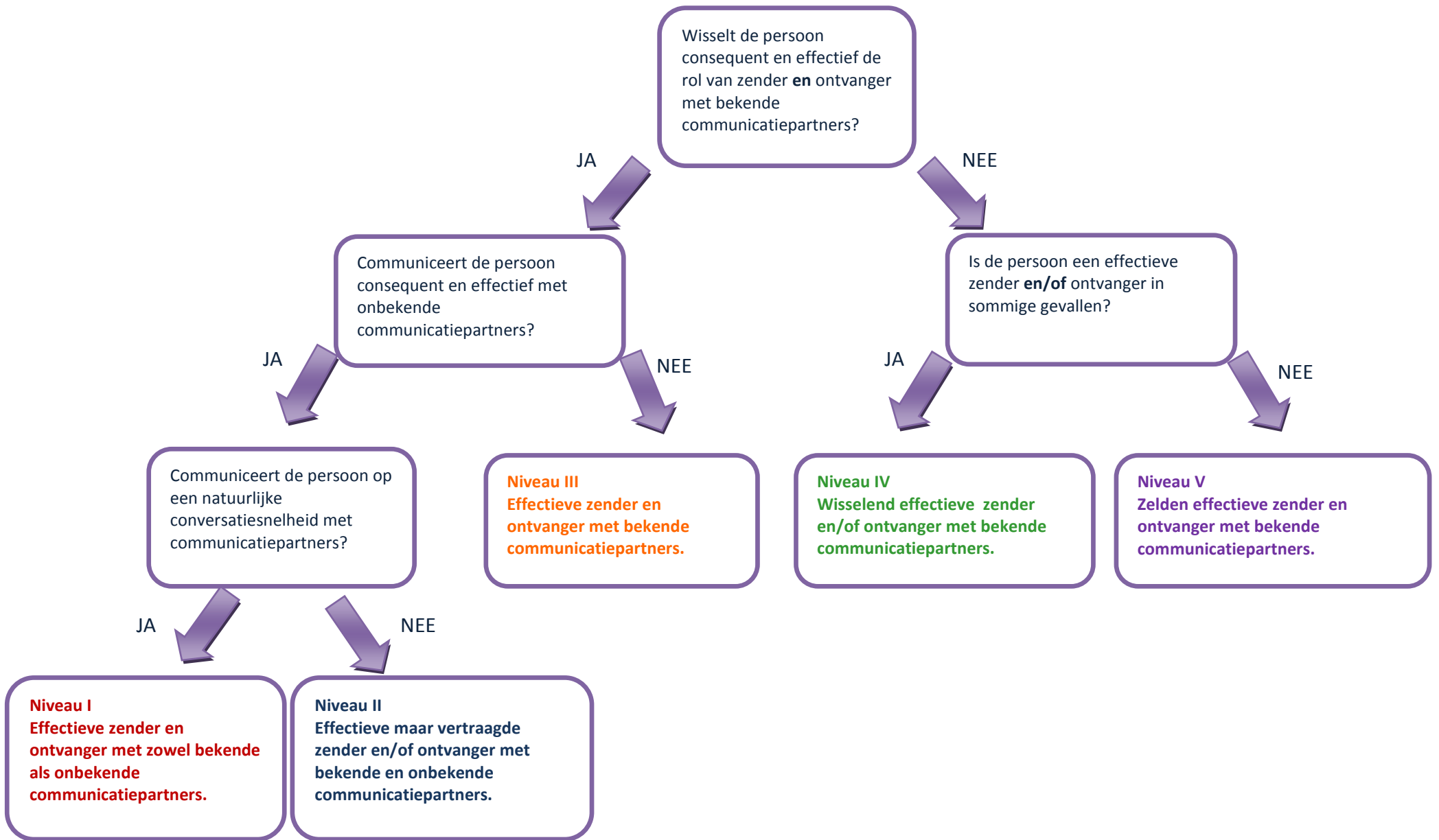


Het verschil tussen niveau III en IV is **in hoeverre de persoon altijd effectief de rol van zender en ontvanger wisselt met bekende communicatiepartners**. Op **niveau III** is de persoon gewoonlijk in staat te communiceren met bekende personen, als zowel zender en ontvanger. Op **niveau IV** is dit niet consequent mogelijk waarbij het probleem kan ontstaan in het zenden en/of ontvangen van de boodschap.



Het verschil tussen niveau IV en V is de **ernst van het communicatieprobleem met bekende communicatiepartners**. Op **niveau IV** is de persoon in sommige gevallen succesvol als zender en/of ontvanger in de communicatie met bekende personen. Op **niveau V** is de persoon zelden in staat om effectief te communiceren zelfs met bekende communicatiepartners.





## APPENDIX B

### CFCs Betrouwbaarheidsonderzoek - CONCEPT VRAGENLIJST

#### 1. Gegevens beoordelaar

##### 1. Wat is uw geslacht?

Vrouw

Man

##### 2. Bent u van Nederlandse afkomst?

JA

NEE

Zo nee, wat is uw afkomst?

##### 3. Wat is uw relatie tot het kind met cerebrale parese?

Ouder van een kind met cerebrale parese

Leerkracht van een kind met cerebrale parese

Logopedist van een kind met cerebrale parese

Anders, nl.

##### 4. Hoeveel jaar ervaring heeft u met kinderen met cerebrale parese?

minder dan 1 jaar

1 – 5 jaar

5 – 10 jaar

meer dan 10 jaar

##### 5. Wat is uw hoogst genoten opleiding?

Geen onderwijs / basisonderwijs / lagere school

LBO / VBO / VMBO

MBO

HBO

Universitair onderwijs

Anders, nl.

## 2. CFCS Classificatie van het kind

Lees voor het beantwoorden van onderstaande vragen het Communicatie Classificatie Functie Systeem (CFCS) zorgvuldig door.

**1. Kruis hieronder het niveau (I, II, III, IV of V) aan dat passend is bij de dagelijkse communicatie van het kind:**

- I. Effectieve zender en ontvanger met zowel bekende als onbekende communicatiepartners
- II. Effectieve maar vertraagde zender en/of ontvanger met bekende en onbekende communicatiepartners
- III. Effectieve zender en ontvanger met bekende communicatiepartners.
- IV. Wisselend effectieve zender en/of ontvanger met bekende communicatiepartners.
- V. Zelden effectieve zender en ontvanger zelfs met bekende communicatiepartners

**2. Hoe zeker bent ervan dat u het kind juist geclassificeerd heeft?**

- Heel zeker
- Redelijk zeker
- Niet zeker

**3. Indien u opmerkingen heeft over het vaststellen van het CFCS niveau kunt u deze hier noteren. Ook eventuele moeilijkheden die u heeft ondervonden bij het lezen van de tekst en het vaststellen van het niveau kunt u hier opschrijven.**

**4. Hoe lang kent u het kind al?**

- minder dan een maand
- 1 tot 6 maanden
- 7 tot 12 maanden
- meer dan 1 jaar
- meer dan 5 jaar
- het hele leven van het kind
- anders, nl.

**5. In welke omgeving heeft u contact met kind?**

- Thuis
- School
- Medische setting (ziekenhuis, revalidatiecentrum, praktijk)
- Anders, nl.

### 3. Gegevens kind

**1. Wat is het geslacht van het kind?**

- Meisje  
 Jongen

**2. Wat is de geboortedatum van het kind**

**3. Is het kind van Nederlandse afkomst?**

- Ja  
 Ne

Zo nee, wat is de afkomst van het kind?

**4. Kunt u het type cerebrale parese van het kind beschrijven?**

- Spastisch (krampachtig; verhoging van de spierspanning)

Is de spasticiteit:

- Unilateraal (éénzijdig, hemiparese)  
 Bilateraal (tweezijdig, diplegie, tetraparese, quadriplegie)

- Dyskinetisch (zich af en toe herhalende tijdelijke bewegingen)

Is de dyskinesie:

- Athetotisch (onwillekeurige buig- en strekbewegingen van vingers en tenen)  
 Choreatisch (plotselinge onwillekeurige gecoördineerde bewegingen)  
 Dystonisch (wisselende spierspanning met neiging tot hypertonie)

- Atactisch (wordt gekenmerkt door balansstoornissen en coordinatiestoornissen)

- Niet geclassificeerd

- Anders, nl.

**5. Zijn er nog andere beperkingen die van toepassing zijn op het kind?**

- Epilepsie  
 Autisme / PDD-NOS  
 Ernstige verstandelijke beperking (IQ lager dan 50)  
 Lichte verstandelijke beperking (IQ tussen 50 en 70)  
 Ontwikkelingsachterstand  
 Gehoorstoornis  
 Visusstoornis  
 Taalstoornis  
 Dysarthrie

- Apraxie
- Gedragsstoornis
- Anders, nl.

**6. Op welke manier communiceert het kind met zijn/haar omgeving?**

- Spraak
- Geluiden (bijvoorbeeld 'aaah' om iemand zijn aandacht te trekken)
- Lichaamstaal, gedrag, kijken, mimiek, gebaren en/of wijzen
- Gebaren (ondersteunde gebaren of gebarentaal)
- Communicatieboek, aanwijskaarten/bladen en/of afbeeldingen (foto's, pictogrammen)
- Communicatieapparaat (met spraakuitvoer)
- Anders, nl.

**7. Wat is het Gross Motor Function Classification System (GMFCS) niveau van het kind?**

- I. Loopt zonder belemmeringen
- II. Loopt zonder hulpmiddelen
- III. Loopt met hulpmiddelen
- IV. Zelf voortbewegen met belemmeringen
- V. Zelf voortbewegen is ernstig belemmerd zelfs met het gebruik van hulpmiddelen.
- Niet bekend

**7. Wat is het Manual Ability Classification System (MACS) niveau van het kind?**

- I. Hanteert objecten gemakkelijk en met succes
- II. Hanteert meeste objecten, maar met iets verminderde kwaliteit en/of snelheid van uitvoering
- III. Hanteert objecten met moeite; heeft hulp nodig bij het voorbereiden en/of aanpassen van activiteiten
- IV. Hanteert een beperkte selectie van makkelijk hanteerbare objecten in aangepaste situaties
- V. Hanteert objecten niet en heeft een ernstig beperkte vaardigheid om zelfs simpele acties uit te voeren
- Niet bekend

**4. Opmerkingen met betrekking tot het onderzoek naar de CFCS**

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