



Universiteit Utrecht
Opleiding MSc Logopediewetenschap
Clinical Language, Speech, and Hearing Sciences

Master's Thesis

**Communication performance of children with
Cerebral Palsy: relation with spoken language
comprehension and contextual factors**

Karlijn van der Zwart
3511090

Supervisie:
drs. J.J.M. Geytenbeek
prof. Dr. P.H. Dejonckere

August 14, 2012

Abstract

Aim: The aim of the present study was to investigate the relationship between everyday communication performance and the level of spoken language comprehension in children with cerebral palsy (CP). Beside spoken language comprehension, the role of contextual factors is also examined.

Participants: 59 children with CP (35 males, 24 females; mean age 6y 10m; SD 2y 4m; range 2y 9m-11y 10m) participated in the present study. Distribution of type of CP was 49.2% with bilateral spastic CP, 13.6% with unilateral spastic CP, 18.6% with dyskinetic CP, 1.7% with ataxic CP and 13.6% with mixed CP. The percentage of children classified as GMFCS levels I to V was 15.3%, 13.6%, 8.5%, 22.0% and 39.0% respectively (1.7% unknown).

Method: Parents, teachers and speech and language therapists (SLT) of the child with CP were sent a survey to classify the communication performance of the child with the Communication Function Classification System (CFCS). In addition, information was collected about contextual factors such as type of CP, level of Gross Motor Function Classification System (GMFCS), the method of communication (verbal, non verbal and/or using augmentative and alternative communication) and associated impairments. SLT reported the level of spoken language comprehension. Depending on age and motor abilities of the child, different language tests were used to the measure level of spoken language comprehension.

Results: The communication performance of children with CP classified by SLT was strongly correlated with the level of spoken language comprehension ($r=.62, p \leq .01$) and the methods of communication ($r=.69, p \leq .01$). A moderate correlation was demonstrated in the classification of parents (level of spoken language comprehension: $r=.49, p \leq .01$ and methods of communication: $r=.43, p \leq .01$). Communication performance (classified by SLT) and GMFCS level was moderately correlated ($r=.58, p \leq .01$), just as the sum of associated impairments ($r=.48, p \leq .01$).

Interpretation: The method of communication and the level of spoken language of a child with CP seem most strongly related to their everyday communication performance.

Abbreviations:

AAC = Alternative and Augmentative Communication

C-BiLLT = Computer-Based instrument for Low motor Language Testing

CFCS = Communication Function Classification System

CP = Cerebral Palsy

GMFCS = Gross Motor Function Classification System

MACS = Manual Ability Classification System

SCPE = Surveillance of Cerebral Palsy in Europe

SLT = Speech and Language Therapy or Speech and Language Therapist(s)

VABS = Vineland Adaptive Behavior Scale

Introduction

Cerebral palsy (CP) is 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 (Bax et al., 2006). The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behavior and by secondary musculoskeletal problems (Rosenbaum et al., 2007 and Fung et al., 2002). The prevalence of CP in Europe is 2.08/1000 live births (SCPE, 2002). CP can be diagnosed at the age of 2 years (Rosenbaum et al., 2007, Bax et al., 2006).

However, due to diversity in type, etiology, and severity, children with CP are a heterogeneous group (Rosenbaum et al., 2007, Meihuizen- de Regt et al., 2009). Consensus about the classification of subgroups of CP is reached by Surveillance of Cerebral Palsy in Europe, SCPE, (2000) (shown in appendix I). This is based on clinical features but does not describe the consequences of the disability. Thus, it is recommended that the diagnosis is used in combination with functional classifications (Rosenbaum et al., 2007, Meihuizen- de Regt et al., 2009, Ohrvall et al., 2010, Himmelman et al., 2006).

In the past years, three classification systems were developed to classify the functional abilities of children with CP. These classification systems are 1) the GMFCS (Gross Motor Function Classification System, Palisano et al., 1997), 2) the MACS (Manual Ability

Classification System, Eliasson et al., 2006) and, 3) the CFCS (Communication Function Classification System, Hidecker et al., 2011).

- 1) GMFCS focuses on self-initiated movement with emphasis on sitting (trunk balance and control) and walking.
- 2) MACS classifies how children with CP use both hands when handling objects in daily activities.
- 3) The CFCS (extended version in appendix II) classifies everyday communication performance of an individual with CP. The overall effectiveness of the communication performance is classified.

All classification systems classify into one of five descriptive levels (shown in table 1). Level I represents the most functional performance. Level V represents the least functional performance.

All systems classify the performance of an individual and do not classify the capacity. Performance refers to what an individual actually does (participation) while capacity refers to what an individual can do in perfect circumstances (activity). These qualifiers are also a part of the International Classification of Functioning, Disability and Health (ICF, appendix III) of the World Health Organization (<http://www.who.int/classifications/icf/en/>).

ICF is a classification of health and health-related domains. This classification system provides information about the body functions and structure and information about activity and participation. ICF also includes the effect of contextual factors. Contextual factors are divided into environmental factors and personal factors. These contextual factors are very important in communication performance because communication depends mainly on environmental factors. Communication is the exchange of information between people and it occurs when a sender transmits a message and a receiver understands the message (Hidecker et al., 2011).

Disorders in communication often occur in children with CP. The presence and the severity of the communication problems are related to the severity of the brain lesion (Geytenbeek et al., in progress, Voorman et al., 2010, Pirila et al., 2007). The motor impairment is causing speech impairments such as dysarthria and anarthria. Additional,

language disorders and cognitive processing deficits are related to communication problems in children with CP.

Voorman et al. (2010) found that the prevalence of communication problems based on the GMFCS level were present in level I in 58% of the children, in level II in 81%, in level III in 85%, in level IV 85%, and in level V 100%. However, the communication problems in this study were measured with the Vineland Adaptive Behavior Scale (VABS, Sparow et al., 1997). This instrument only measures the expressive skills (skills of a sender). The receptive skills (receiver) were not determined in this assessment. The children's method of communication differs as a result of the diversity in communication problems. The study of Sigurdardottir and Vik (2011) reported that 84% of the children communicated verbally. It has been estimated that approximately 20% of children with CP communicate non-verbally (Pennington et al., 2005, Sigurdardottir and Vik, 2011, Anderson et al., 2010). Additionally, children with severely speech impairment or no speech communicated with the use of alternative and augmentative communication (AAC) methods. About 14% of the children with CP used AAC methods in the study of Sigurdardottir and Vik (2011). Common used AAC methods are (Hidecker et al., 2011): sounds, eye gaze, facial expressions, gesturing, and/or pointing, manual signs, communication book, boards, and/or pictures, voice output device or a speech-generating device.

To provide a complete picture about the communication abilities of a child with CP in daily life, the level of communication performance, methods of communication and level of language comprehension are important to know.

Therefore, the primary aim of the present study is to investigate the relation between communication performance (measured with CFCS) and level of language comprehension in children of 2y 9m to 12y with a diagnosed CP. The present study also attempts to answer which contextual factors may have influence on the level of the communication performance of the child with CP.

These aims will be addressed by the following two null-hypotheses:

- 1) There is no significant difference in communication performance between children with severely delayed, delayed and average spoken language comprehension.

- 2) Contextual factors (type of CP, level of GMFCS, method of communication) and associated impairments do not have any influence on communication performance in children with CP.

Method

PARTICIPANTS

Participants were 59 children with CP (mean age 6y 10m; SD 2y 4m, age range 2y 9m - 11y 10m) with GMFCS levels I (15.3%), II (13.6%), III (8.5%), IV (22.0%) and V (39.0%). Children were recruited from six rehabilitation centers in the Netherlands. Additionally, eleven of the 59 were collected from a longitudinal study of children with severe CP with GMFCS level IV and V (Geytenbeek et al., in process)

The characteristics of the participants are presented in table 2.

PROCEDURE AND INSTRUMENT

Parents, SLT and teachers of the children with CP were sent a survey by email (see appendix IV). Responses were returned digitally and automatically to the researcher when the parents, teachers and SLT of the child s had completed the survey on their computer.

The survey consisted of questions related to the communication performance of the child. The CFCS was used to classify the communication performance of children with CP. All methods of communication are considered in determining the CFCS level (Hidecker et al., 2011). The distinctions between the CFCS levels are based on the performance of sender and receiver roles, the pace of conversation and the type of conversational partner (familiar or unfamiliar). The interrater reliability of both the English and Dutch version of the CFCS between professionals, parents and SLT has proven to be good (Hidecker et al., 2011, De Kleijn et al., to be submitted). In the present study, the interrater reliability between parents and SLT was $\kappa = .44$ (95% Confidence Interval (CI) = .26-.62). However, the interrater reliability between parents and teachers and SLT and teachers was $\kappa = 0.19$ (95% CI 0.00-0.42) and $\kappa = 0.29$ (95% CI 0.06-0.53) respectively. Because of this low interrater reliability, the responses of the teachers were excluded from further analyses.

Beside information about the communication performance, additional information was collected about the following contextual factors:

- Type of CP: unilateral spastic CP, bilateral spastic CP, dyskinetic CP, ataxic CP or otherwise
- Level of GMFCS: I, II, III, IV, V
- Method of communication, defined as verbal, non verbal and using talking device.
- Level of spoken language comprehension: depending on age and motor abilities of the child, different language tests were used to measure level of spoken language comprehension: Reynell Test voor Taalbegrip (van Eldik et al., 1995), Schlichting Test voor Taalbegrip (Schlichting et al., 2011), Clinical Evaluation Language Fundamentals (CELF) Zinnen Begrijpen (Kort et al., 2008), CELF Begrijpen en Aanwijzingen Volgen (Kort et al., 2008) or Computer-Based instrument for Low motor Language Testing (C-BiLLT, Geytenbeek et al., 2010). Because percentile scores are provided for all these tests comparison between level of spoken language comprehension could be made and was defined as severely delayed (language score of percentile <3), delayed (language score between percentile 3-15) or average (language score of percentile >15).
- Associated impairments: the presence of the following associated impairments was reported by SLT: epilepsy, cognitive impairment (IQ < 70), speech impairment (anarthria or dysarthria), autism spectrum disorder, hearing impairment, nutrition problems, visus impairment.

The sum of associated impairments was interpreted as the severity of the associated impairments. To interpret the results, there is a difference between none, one and two or more associated impairments.

DATA ANALYSIS

Spearman's rank correlation coefficient was used to determine the relation between CFCS levels and contextual factors. Spearman's correlation was interpreted as follows (Swinscow, 1996): $r \geq 0.80$ very strong relationship; $0.60 \leq r < 0.80$ strong relationship; $0.40 \leq r < 0.60$ moderate relationship; $0.20 \leq r < 0.40$ weak relationship; $r < 0.20$ very weak relationship. A probability level of $p \leq 0.01$ was considered statistically significant. Logistic regression (enter method) was performed to determine the probability that a child had a less effective communication performance (classified by SLT) and how

associated impairments could explain this communication performance. In these analyses, a binominal distribution of the CFCS was used as the dependent variable (levels I and II combined, and levels III, IV and V combined). CFCS level I and II were combined because the communication performance in these levels is effective with familiar and unfamiliar partners. CFCS level III, IV and V were combined because children in these levels communicate not consistently effective with unfamiliar partners. The CFCS was the dependent variable. Level of spoken language comprehension and the following associated impairments were entered as predictors: cognitive impairment, epilepsy, and speech impairment.

Level of spoken language comprehension was a categorical variable. The reference category was percentile score <3. The associated impairments were entered as dichotomous variable.

Analyses were performed with SPSS version 20.0.

Results

The results are based on responses of parents and SLT. The response rate of the parents was 88% and the response rate of SLT was 89%.

DISTRIBUTION OF CFCS LEVELS RELATED TO TYPE OF CP

The correlation between CFCS levels and type of CP was $r=.36$ ($p \leq .01$). Figure 1 shows the results of the CFCS levels distributed by type of CP.

Children with mild motoric impairments (unilateral spastic CP) were classified as CFCS level I (28.6%), as II (28.6%), as III (42.9%). Children with dyskinetic CP were classified as CFCS level II (20.0%), III (30.0%), IV (40.0%) and V (10.0%). Also children with mixed CP were classified as CFCS level II (14.3%), III (14.3%), IV (42.9%) and V (28.6%). Children with bilateral spastic CP were classified in every CFCS level: I (19.2%), II (11.5%), III (23.1%), IV (42.3%), V (3.8%). As a result, most of the children in the present study were classified as CFCS level IV, regardless of the type of CP, with an exception of the children with a mild motoric impairment (i.e. none of the children with unilateral spastic CP is classified as CFCS level IV).

DISTRIBUTION OF CFCS LEVELS RELATED TO GMFCS LEVELS

GMFCS levels were significantly correlated with CFCS levels ($r=.58, p \leq .01$). Figure 2 shows the distribution of CFCS related to GMFCS levels. Twenty-eight percent of the children had the same classification level for the two systems. Yet, 71.6% of the children were classified in different GMFCS and CFCS levels: 49.0% of 71.6% of the children were classified in a higher GMFCS level than CFCS level (shown in table 3).

DISTRIBUTION OF CFCS LEVELS RELATED TO METHODS OF COMMUNICATION

CFCS levels and methods of communication correlated significantly classified by parents ($r=.43, p \leq .01$) and by SLT ($r=.69, p \leq .01$). Figure 3 shows the distribution of CFCS levels related to methods of communication.

CFCS level I only included children who communicated verbally classified by SLT and by parents (except for one child). None of the verbal children were classified as CFCS level V.

The group of nonverbal children rated by parents was classified as CFCS level III (37.5%), IV (25.0%) or V (25.0%) and also by SLT as CFCS levels III (14.3%), IV (42.9%) and V (42.9%).

Children who communicated with a talking device were classified by parents as CFCS level II (30.0%), III (40.0%), IV (30.0%). SLT classified the majority of the children with a talking device as level IV (73.3%). Beside, 6.7% were classified as CFCS level II, 13.3% as level III and 6.7% as level V.

DISTRIBUTION OF CFCS LEVELS RELATED TO LEVELS OF SPOKEN LANGUAGE COMPREHENSION

Levels of spoken language comprehension correlated significantly with the level of communication performance as classified by parents ($r=.49, p \leq .01$) and by SLT ($r=.62, p \leq .01$). The distribution of CFCS levels related to levels of spoken language comprehension is shown in figure 4.

Both parents and SLT classified children with an average level of comprehension in CFCS level I, II, III and IV. The majority of the parents classified these children as CFCS level II (58.8%). Beside, level I included 11.8%, level III included 23.5% and level IV included 5.9% of the children with average spoken language comprehension. However, the distribution of CFCS levels related to an average spoken language comprehension

performance varies more in SLT's classification: 29.4% is classified as CFCS level I, 35.3% is classified in CFCS level II and both CFCS level III and IV included 17.6%.

All children with delayed spoken language comprehension were classified as CFCS level I, II and III by parents (resp. 16.7%, 50.0%, 33.3%) and by SLT (CFCS level I, II and III included 33.3% of the children).

The majority of the children who showed severely delayed comprehension were classified as CFCS level IV (parents: 38.9% and SLT: 54.5%). In addition, parents classified 5.6% of these children as CFCS level I, 16.7% as level II, 27.8% as level III and 11.1% as level V. SLT classified 4.5% as level II, 27.3% as level III and 13.6% as level V. However, all children classified as CFCS level V showed severely delayed comprehension (percentile <3) both by parents and SLT.

INFLUENCE OF ASSOCIATED IMPAIRMENTS ON CFCS LEVELS

Ten percent of the children with CP had no associated impairments, 31% had one associated impairment and 59% of the children had two or more associated impairments.

The number of associated impairment had a significant relation with the level of communication performance ($r = .48, p \leq .01$). Figure 5 shows the distribution of the number of associated impairments related to the CFCS. Children without associated impairments were classified as CFCS level I. One child without associated impairments is classified as CFCS level II and one child as level IV.

Children with one associated impairment were classified as level I (18.8%), II (31.2%), III (25.0%) and IV (25.0%).

Children with two or more associated impairments were classified in all CFCS levels (resp. 3.3%, 10.0%, 30.0%, 43.3%, 13.3%). Only children with two or more associated impairments were classified as CFCS level V.

Logistic regression analyses suggested that severely delayed spoken language comprehension (language score of percentile <3) and delayed spoken language comprehension (percentile 3-15) are the only factors to predict a less effective communication performance. The singular associated factors are not related to predict a less effective communication performance. The results of the regression are shown in table 4.

Discussion

The aim of the present study was to investigate the communication performance of children with CP in relation to their level of language comprehension and to investigate or contextual factors and additional impairments have an impact on the communication performance.

DISTRIBUTION OF CFCS LEVELS RELATED TO TYPE OF CP

The sample of the present study corresponded with the population of children with CP (SCPE, 2002).

A weak correlation is shown between communication performance level and type of CP. These results are in line with previous research. Bax et al. (2011) showed that communication problems occurred in every type of CP. Voorman et al. (2006) described that the type of CP is significant related to communication problems but cognitive skills and epilepsy were stronger correlated with expressive language skills of children with CP.

DISTRIBUTION OF CFCS LEVELS RELATED TO GMFCS LEVELS

Severity of motor involvement was moderately correlated with the communication performance in children with CP. Also Hidecker et al. (2012) investigated the relationship among the GMFCS and CFCS in children with CP. Their findings showed that GMFCS levels were also moderately correlated with CFCS levels ($r=0.47, p \leq .01$). In addition, Voorman et al. (2010) showed that a higher level of GMFCS is associated with a higher percentage of communication problems: 58% of the children classified as GMFCS I had communication problems while 100% of the children classified as GMFCS V had communication problems.

DISTRIBUTION OF CFCS LEVELS RELATED TO METHODS OF COMMUNICATION

The method of communication was significantly correlated with CFCS levels. The difference in classifying by parents (moderate correlation) and classifying by SLT (strong correlation) is notable.

Hidecker et al. (2011) also described the difference in classifying between parents and professionals. They explained this difference as a result of the fact that parents see their child in a range of different environments while professionals only see the child in its

educational environment. Moreover, parents may not be aware of the difficulty unfamiliar communication partners have in communicating with their child. It may also indicate that successful communication is a complex notion that relates as much to a partner's expectations and skills as to the competence of a child with CP.

It is also notable that indicated by SLT more children were using a talking device than indicated by parents. This finding suggests that children only use their talking device in a practice situation and do not use it in their home environment. The use of a talking device can influence the classification of the CFCS (Cockerill, 2011). Also this difference can explain the different classification of communication performance between parents and SLT. Cockerill (2011) noticed that a child may change to different (more effective) level within the CFCS if provided with appropriate AAC systems and training.

In addition, the majority of the children who using a talking device are classified in CFCS level IV by SLT, which means that the child does not consistently alternate sender and receiver roles with their talking device. Sigurdardottir and Vik (2011) also investigated the role of AAC methods in the communication with children with CP. They described that it is challenging to adapt AAC methods to the needs of nonverbal children. It is hard for (nonverbal) children with CP to communicate effectively with their talking device. According to parents, children alternate between sender and receiver roles using their talking device (30% in CFCS level II and 40% in level III). These results also suggest that parents are not aware of the difficulty may be in sending and/ or receiving effectively.

Verbal children were mainly classified in the highest (more effective) levels both by parents (65%) and SLT (52%) but were also classified as CFCS level III and IV, resp. 35% and 48%. In the present study, "verbal" is not further classified. The responses of the survey didn't separate children who speak functionally and children who only produce phrases or single words. It is conceivable that children producing one-word utterances were considered as verbal communicators, and were classified as CFCS level III or IV.

DISTRIBUTION OF CFCS LEVELS TO LEVELS OF SPOKEN LANGUAGE COMPREHENSION

The communication performance of children with CP is strongly related to the level of spoken language comprehension. It is noticeable that the group of children with delayed spoken language comprehension is small (n=6).

It has been reported earlier (Geytenbeek et al., 2010) that children with complex communication needs can develop spoken language comprehension abilities in the absence of productive language. These findings suggest that the communication performance also can change in relation to spoken language comprehension and communication performance. It seems that when spoken language comprehension performances improve, the communication performance of a child becomes more effective.

INFLUENCE OF ASSOCIATED IMPAIRMENTS

The sum of associated impairments had a significant moderate correlation with CFCS levels. Sigurdardottir and Vik (2011) investigated the influence of associated impairments on communication abilities of children with CP. They found that the number of associated impairments is related to the methods of communication. Their findings showed that 88% of the nonverbal children had two or more associated impairments compared with 18% of the verbal group. In the present study the methods of communication and CFCS levels are significantly correlated. The findings of Sigurdardottir and Vik (2011) ratify that the sum of associated impairments are related to methods of communication and communication performance in daily life.

The present study showed that the level of spoken language comprehension is more strongly related to the CFCS levels than epilepsy, cognitive abilities and speech impairments. However, previous research showed a relationship between communication abilities of children with CP and these associated factors (Voorman et al., 2006, Zafeiriou et al., 1999, Sigurdardottir et al., 2008). But none of the described studies investigated the associated impairments compared to the communication performance in daily life.

Zafeiriou et al. (2009) investigated the role of epilepsy on communication and showed that the presence of epilepsy in children with CP was correlated statistically with an increased frequency of speech problems. However, speech problems were not further specified. Also Voorman et al. (2006) investigated the influence of epilepsy on communication and found that epilepsy and cognitive impairment were the most important factors associated to the expressive language skills in children with CP.

Pirila et al. (2007) showed that cognitive functioning could affect the communication abilities in children with CP. Their findings showed that children with an IQ ≥ 70 were less impaired in their expressive language skills than children with an IQ < 70 .

The results of these studies compared to the results of the present study suggest a difference between the effect of associated impairments on the expressive skills and on the communication performance. The singular associated impairments had an effect on expressive skills but don't seem to be an effect on communication in daily life measured with the CFCS. This is in line with the strong correlation between the level of spoken language comprehension and communication performance. The results indicate that the level of spoken language comprehension is very important in the communication in daily life.

LIMITATIONS OF THE PRESENT STUDY

The response rate of parents was 88% and response rate of SLT was 89% but the level of spoken language comprehension was not reported in 23.7% of the children because there is no test available to investigate the spoken language comprehension of children with severe vision impairments.

The response rate of the teachers was 61% as a result of a low response rate of teachers from three rehabilitation centers. The majority of the teachers reported that they had no time to complete the survey. The agreement between teachers and parents and teachers and SLT was low. This means that the teachers are excluded in the present survey. This is noticeable and could be explained by the following reasons: a child communicates more effectively at home compared to the school situation or another possible reason could be that teachers do not have a complete picture of the communication performance of the child in daily life. In addition, 50% of the teachers knew the child shorter than 12 months. In contrary, only 27.5% of the SLT know the child for less than 12 months.

Also there are limitations on the survey because the associated factors were not exactly defined. This may confound the participants.

In addition, the present study was limited to the restrictions of the CFCS: age bounds for communication performance are not given.

RECOMMENDATIONS

Teachers have to be included in future research on contextual factors on the communication performance of children with CP to provide a complete picture. In addition, future research with repeated measures in a longitudinal study is needed to investigate the development of communication performance in children with CP. It would be interesting to see which factors contribute the effectiveness of communication in daily life. Finally, it is useful to develop a course for the use of the CFCS. This will increase the interrater reliability.

Conclusion

These preliminary results suggest that: a) spoken language comprehension is strongly related to the communication performance of children with CP. b) the level of communication performance is related to some extent to contextual factors (i.e. GMFCS and the method of communication). c) the number of the associated impairments has an influence on the communication performance. It is unlikely that the findings occurred by chance, as indicated by the low p values.

Therefore, the following hypotheses can be rejected:

- 1) There is no significant difference in communication performance between children with severely delayed, delayed and average spoken language comprehension.
- 2) Contextual factors (type of CP, level of GMFCS, method of communication) and associated impairments do not have any influence on communication performance in children with CP.

The present study revealed that method of communication and the level of spoken language comprehension were most strongly related to the outcomes of the CFCS or in other words, the method of communication and the level of spoken language of a child with CP seem most strongly related to their everyday communication performance.

Acknowledgements

Many thanks go to the parents, teachers and SLT's of the children for their willingness to cooperate in the present study. I also thank my supervisor's drs. J.J.M. Geytenbeek en

prof. Dr P.H. Dejonckere with special thanks to drs J.J.M. Geytenbeek for her effort to give feedback and transferring her knowledge.

References

1. Bax M., Tydeman C., Flodmark O., (2006), Clinical and MRI Correlates of Cerebral Palsy: the European Cerebral Palsy Study, *American Medical Association*, 296, 1602-1608
2. Cockerill H. (2011), Developing the Communication Function Classification System for individuals with cerebral palsy, *Developmental Medicine & Child Neurology* (commentary)
3. Eldik M.C.M. van, Schlichting J.E.P.T., Lutje Spelberg H.C., Meulen B.F. van der, Meulen S.J. Van der, (1995), Reynell Test voor Taalbegrip, Pearson Assessment and Information B.V.
4. Eliasson A.C., Krumlinde-Sundholm L., Rosblad B., et al. (2006), The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability, *Developmental Medicine & Child Neurology*, 48, 549-554
5. Fung E.B., Samson-Fang L., Stallings, V.A., et al. (2002), Feeding dysfunction in associated with poor growth and health status in children with cerebral palsy, *Journal of the American Dietetic Association*, 102, 361-373
6. Geytenbeek J., Harlaar L., Stam M., et al. (2010), Utility of language comprehension tests for unintelligible or non-speaking children with cerebral palsy: a systematic review, *Developmental Medicine & Child Neurology*, 52, 267-277
7. Geytenbeek J.M., Heim M.J., Vermeulen J., et al. (2010), Assessing Comprehension of Spoken Language in Nonspeaking Children with Cerebral Palsy: Application of a Newly Developed Computer-Based Instrument, *Augmentative and Alternative Communication*, 26, 97-107
8. Geytenbeek J.M., Harlaar, L., Oostrom K. et al. (in process), MRI patterns and language comprehension performance in children with severe CP.
9. Geytenbeek J.M., Heim M.J., Vermeulen J., et al. (in process), Computer-Based Instrument for Low Motor Language Testing

10. Hidecker M.J.C., Ho N.T., Dodge N. et al. (2012), Inter-relationships of functional status in cerebral palsy: analyzing gross motor function, manual ability, and communication function classification systems in children, *Developmental Medicine & Child Neurology*, 54, 737-742
11. Hidecker M.J.C., Paneth, N., Rosenbaum, P.L., et al. (2011). Developing and validating the Communication Function Classification System (CFCS) for individuals with cerebral palsy, *Developmental Medicine and Child Neurology*, 53, 704-710
12. Himmelman K., Beckung E., Hagberg G. et al. (2006), Gross and fine motor function and accompanying impairments in cerebral palsy, *Developmental Medicine & Child Neurology*, 48, 417-423
13. Kleijn M.A.M.C. de, Geytenbeek J.J.M., Gorter J.W. et al. (to be submitted), Validity and reliability of the Dutch language version of the Communication Function Classification System (CFCS-NL)
14. Kort W., Schittekatte M., Compaan E. (2008), *Clinical Evaluation of Language Fundamentals – 4^e editie*, Pearson Assessment and Information B.V.
15. Meihuizen-De Regt M.J., Moor de J.M.H., Mulders A.H.M. (2009), *Kinderrevalidatie*, Koninklijke Van Gorcum, Assen
16. Odding E., Roebroek M.E., Stam H.J. (2006), The epidemiology of cerebral palsy: Incidence, impairments and risk factors, *Disability and Rehabilitation*, 28, 183 – 191
17. Ohrvall A.M., Eliasson A.C., Lowing K. et al. (2010), Self-care and mobility skills in children with cerebral palsy, related to their manual ability and gross motor function classifications, *Developmental Medicine & Child Neurology*, 52, 1048-1055
18. Palisano R., Rosenbaum P., Walter S., et al. (1997), Development and validation of a Gross Motor Function Classification System for children with cerebral palsy, *Developmental Medicine & Child Neurology*, 39, 214-223
19. Pennington L, Goldbar J, Marshall J. (2005), Direct speech and language therapy for children with cerebral palsy: findings from a systematic review, *Developmental Medicine & Child Neurology*, 47, 57-63

20. Pirila S, Meere J. van der, Pentikainen T. et al. (2007), Language and motor speech skills in children with cerebral palsy, *Journal of Communication disorders*, 40, 116 - 128
21. Rosenbaum P., Paneth N., Leviton A., et al. (2007), A report: the definition and classification of cerebral palsy April 2006, *Developmental Medicine & Child Neurology Supplement*, 109, 8-14
22. SCPE (2000), Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers, *Developmental Medicine & Child Neurology*, 42, 816-824
23. SCPE (2002), Prevalence and characteristics of children with cerebral palsy in Europe, *Developmental Medicine & Child Neurology*, 44, 633-640
24. Schlichting J.E.P.T., Lutje Spelberg H.C. (2011), Schlichting Test voor Taalbegrip, Bohn Stafleu van Loghum
25. Sigurdardottir S., Vik T. (2011), Speech, expressive language, and verbal cognition of preschool children with cerebral palsy in Iceland, *Developmental medicine and Child Neurology*, 53, 74-80
26. Sigurdardottir S., Eiriksdottir A., Gunnarsdottir E., et al. (2008), Cognitive profile in young Icelandic children with cerebral palsy, *Developmental Medicine & Child Neurology*, 50, 357-362
27. Sparow S.S., Balla D.A., Cicchetti D.V. (1997), Vineland Adaptive Behavior Scales, Leiden: Rijksuniversiteit Leiden, Vakgroep orthopedagogiek
28. Swinnow T.D.V, revised by M J Campbell (1996), *Statistics at square one 9th edition*, BMJ Publishing Group, London
29. Voorman J.M., Dallmeijer A.J., Schuengel C. et al. (2006), Activities and participation of 9- to 13-year-old children with cerebral palsy, *Clinical Rehabilitation*, 20, 937-948
30. Voorman J.M., Dallmeijer A.J., Eck van M. et al. (2010), Social functioning and communication in children with cerebral palsy: association with disease characteristics and personal and environmental factors, *Developmental Medicine & Child Neurology*, 52, 441-447
31. Zafeiriou D.I., Eleftherious E.K., Tsikoulas I. (1999), Characteristics and prognosis of epilepsy in children with cerebral palsy, *Journal of child Neurology*, 14, 289-294
32. <http://www.who.int/classifications/icf/en/> (July 2012)

Tables and graphs

Table 1: Levels of GMFCS, MACS and CFCS to classify the functional abilities of children with CP (Hidecker et al., 2011)

	GMFCS	MACS	CFCS
Level I	Walks without limitations	Handles objects easily and successfully	Sends and receives with familiar and unfamiliar partners effectively and efficiently
Level II	Walks with limitations	Handles most objects but with somewhat reduced quality and/or speed of achievement	Sends and receives with familiar and unfamiliar partners but may need extra time
Level III	Walks using a hand-held mobility device	Handles objects with difficulty; needs help to prepare and/or modify activities	Sends and receives with familiar partners effectively, but not with unfamiliar partners
Level IV	Self-mobility with limitations; may use powered mobility	Handles a limited selection of easily managed objects in adapted situations	Inconsistently sends and/ or receives even with familiar partners
Level V	Transported in a manual wheelchair	Does not handle objects and has severely limited ability to perform even simple actions.	Seldom effectively sends and receives, even with familiar partners

Table 2: characteristics of the children

n	59
Mean age	6y 10m
Age range	2y 9m - 11y 10 m
Gender	Male: 35 (59.3%) Female: 24 (40.7%)
Type CP	Spastic unilateral CP: 8 (13.6%) Spastic bilateral CP: 30 (50.8%) Dyskinetic CP: 11 (18.6%) Ataxic CP: 1 (1.7%) Mixed CP: 8 (13.6%) Not specified: 1 (1.7%)
GMFCS levels	I: 9 (15.3%) II: 8 (13.6%) III: 5 (8.5%) IV: 13 (22.0%) V: 23 (39.0%) Unknown: 1 (1.7%)

Table 3: Association between levels of CFCS (classified by SLT) and GMFCS

	CFCS I	CFCS II	CFCS III	CFCS IV	CFCS V	Total
GMFCS I	9.8% 5	3.9% 2	2.0% 1	2.0% 1	0% 0	17.6% 9
GMFCS II	0.0% 0	3.9% 2	7.8% 4	2.0% 1	0.0% 0	13.7% 7
GMFCS III	0.0% 0	3.9% 2	2.0% 1	2.0% 1	0% 0	7.8% 4
GMFCS IV	3.9% 2	3.9% 2	3.9% 2	7.8% 4	2.0% 1	21.6% 11
GMFCS V	0.0% 0	2.0% 1	9.8% 5	21.6% 11	5.9% 3	39.2% 20
Total	13.7% 7	17.6% 9	25.5% 13	35.3% 18	7.8% 4	100.0% 51

Total number of children is shown in grey, a total agreement is shown in bold.
 $r = .583$ ($p \leq .01$)

Table 4: Outcomes of logistic regression (enter method)

	B (S.E.)	Sig.	95% CI for Odds Ratio (Exp(B))		
			Lower	Odds Ratio	Upper
Constant	2.122 (1.275)	.096		8.351	
Spoken language comprehension: Severely delayed (reference category)		.024			
Moderate	-3.369 (1.299)	.010*	.003	.034	.439
Delayed	-3.184	.020	.003	.041	.601
Cognitive impairment	.323 (1.251)	.796	.119	1.381	16.039
Speech impairment	.510 (.865)	.556	.306	1.665	9.071
Epilepsy	1.802 (1.378)	.191	.407	6.059	90.315

Note: $R^2 = .390$ (Cox & Snell), $.531$ (Nagelkerke). Model $\chi^2(1) = 20.791$ $p \leq .01$

* $p \leq .01$, which means that the effect of moderate spoken language comprehension significantly differed from the severely delayed spoken language comprehension in relation to a less effective communication performance

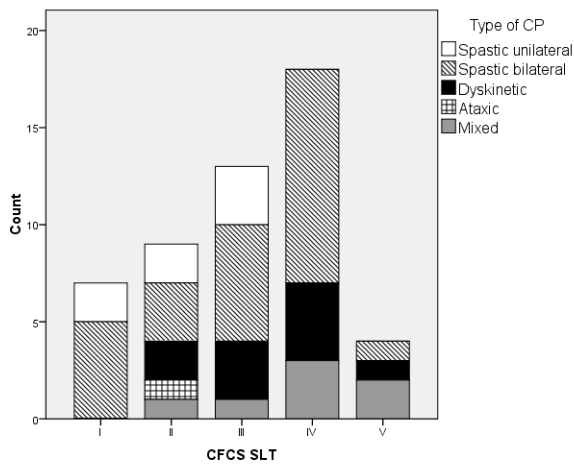


Figure 1: Distribution of CFCS levels related to type of CP (n SLT = 51)

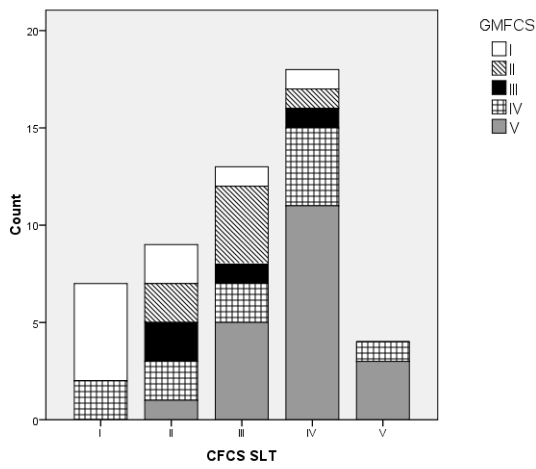


Figure 2: Distribution of CFCS levels related to GMFCS levels (n SLT = 51)

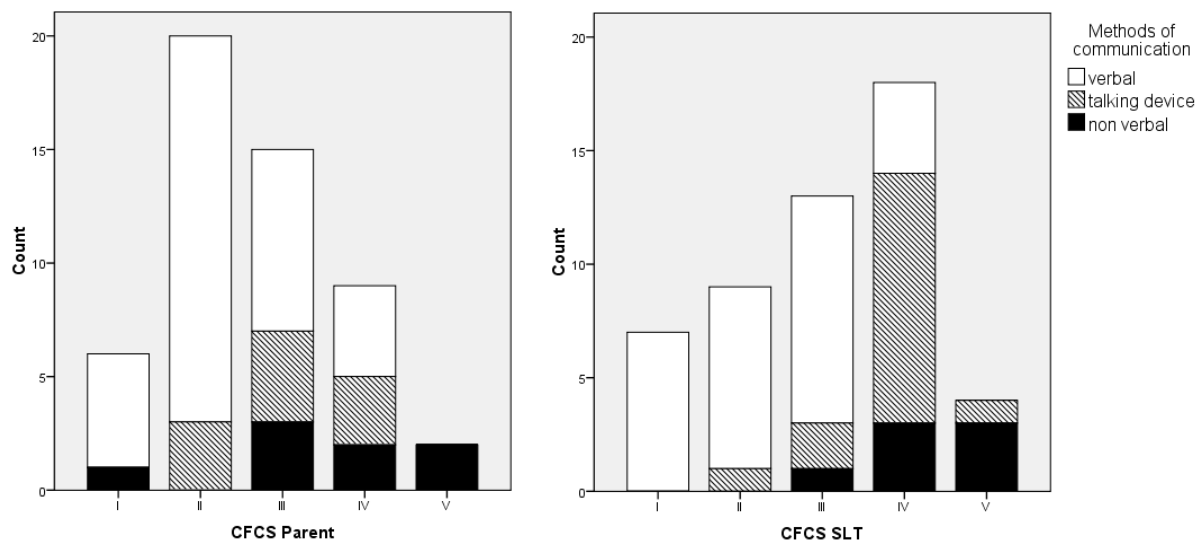


Figure 3: Distribution of CFCS levels related to methods of communication (n parent = 52, n SLT = 51)

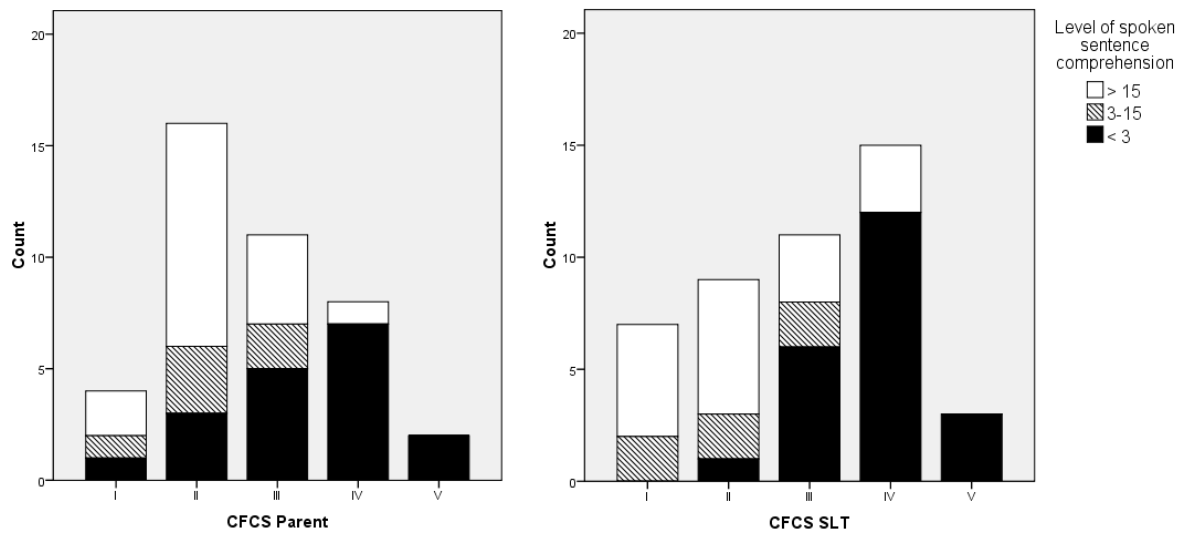


Figure 4: Distribution of CFCS levels related to levels of spoken language comprehension (n parent = 41, n SLT = 45)

Percentile > 15 = moderate, percentile 3-15 = delayed, percentile <3 = severely delayed

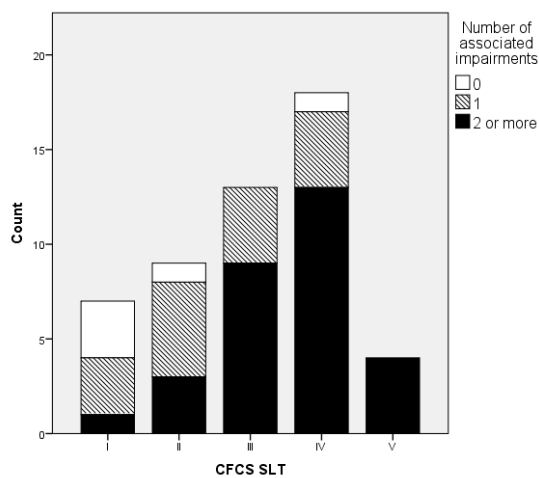


Figure 5: Distribution of CFCS levels related to number of associated impairments

Appendix I: definitions for each subtype CP (SCPE, 2000)

Spastic CP is characterized by at least two of:

- Abnormal pattern of posture and/ or movement
- Increased tone (not necessarily constant)
- Pathological reflexes (increased reflexed: hyperreflexia and/or pyramidal signs e.g. Babinski response)

Spastic CP may be either bilateral or unilateral

Spastic bilateral CP is diagnosed if:

Limbs on both sides of the body are involved

Spastic unilateral CP is diagnosed if:

Limbs on one side of the body are involved

Ataxic CP is characterized by both:

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

Dyskinetic CP is dominated by both:

- Abnormal pattern of posture and/or movement
- Involuntary, uncontrolled, recurring, occasionally stereotyped movements

Dyskinetic CP may be either dystonic or choreo-athetotic

Dystonic CP is dominated by both:

- Hypokinesia (reduced activity, i.e. stiff movement)
- Hypertonia (tone usually increased)

Choreo-athetotic CP is dominated by both:

- Hyperkinesia (increased activity, i.e. stormy movement)
- Hypotonia (tone usually decreased)

Appendix II: Communication Function Classification System

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

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.

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 misunderstandings are often repaired and do not interfere with the eventual effectiveness of the person's communication with both **unfamiliar and familiar partners**.

III. Effective Sender and Receiver with familiar partners.

The person **alternates between sender and 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**.

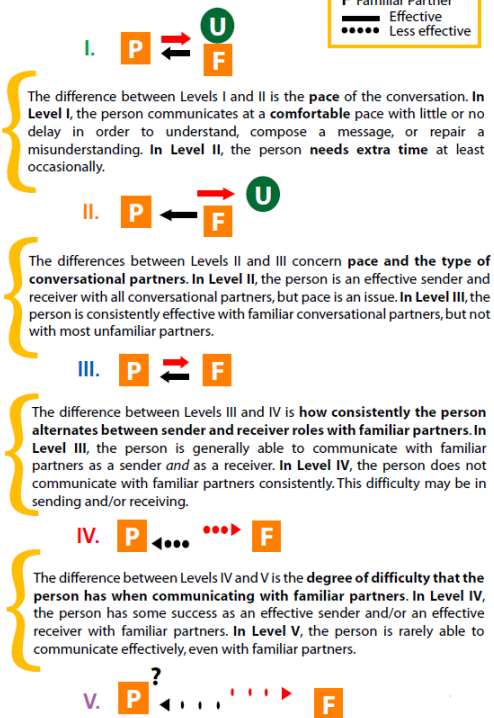
IV. Inconsistent Sender and/or Receiver with familiar partners.

The person does **not** 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**.

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

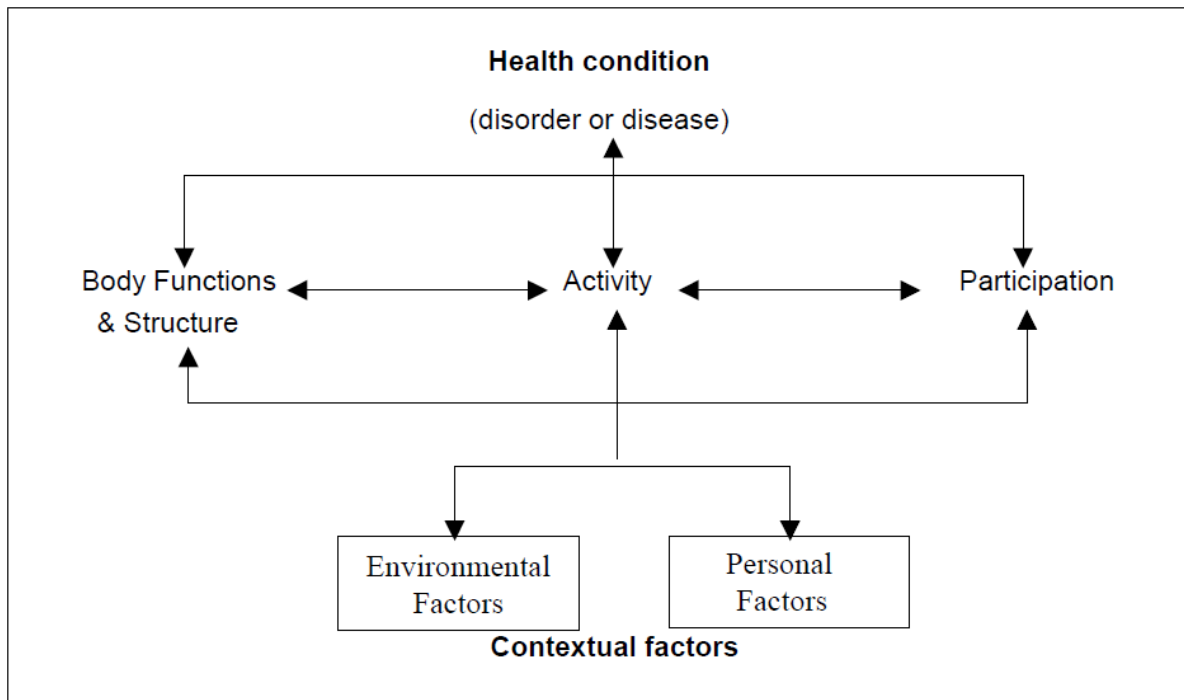
The person is limited as both a **sender and a receiver**. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is **seldom effective** even with **familiar partners**.

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



Appendix III: ICF model and the formal definitions

<http://www.who.int/classifications/icf/en/> (July 2012)



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..

Appendix IV: Aspects of survey, including the references

General information about the child

Question	Answer*	References
Name		Existing survey**
Gender		Existing survey
Birth date		Existing survey
Nationality		Existing survey

*o means one possibility to answer; □ means more possibilities to answer

**De Kleijn et al (to be submitted)

Information about the rater

Question	Answer*	References
What is your relation to the child?	<ul style="list-style-type: none"> ○ Parent of child with CP ○ Teacher of child with CP ○ SLT of child with CP ○ Other... 	Existing survey
What is your highest education level?	<ul style="list-style-type: none"> ○ No Education/ Preliminary school ○ LBWO/ VBO/ VMBO ○ MBO ○ HBO ○ University ○ Other... 	Existing survey
What is your nationality?		Existing survey
How long do you know the child?	<ul style="list-style-type: none"> ○ < one month ○ 1-6 months ○ 7-12 months ○ > one year ○ whole life of the child 	Existing survey

<p>In what environment do you meet the child?</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Home <input type="checkbox"/> School <input type="checkbox"/> Medical setting (hospital, rehabilitation centre etc.) <input type="checkbox"/> Other... 	<p>Existing survey</p>
---	--	------------------------

CFCS Classification of the child

Question	Answer*	References
<p>Which level is the most appropriate to the child's communication in daily life?</p>	<ul style="list-style-type: none"> <input type="radio"/> Sends and receives with familiar and unfamiliar partners effectively and efficiently <input type="radio"/> Sends and receives with familiar and unfamiliar partners but may need extra time <input type="radio"/> Sends and receives with familiar partners effectively, but not with unfamiliar partners <input type="radio"/> Inconsistently sends and/ or receives even with familiar partners <input type="radio"/> Seldom effectively sends and receives, even with familiar partners 	<p>Existing survey Hidecker et al (2011)</p>
<p>How sure are you that you have classified correctly?</p>	<ul style="list-style-type: none"> <input type="radio"/> Very sure <input type="radio"/> Reasonable sure <input type="radio"/> Not sure 	<p>Existing survey</p>
<p>When you have</p>		<p>Existing survey</p>

<p>additional comments about the classification of the CFCS, you can note them here.</p>		
--	--	--

Additional information about the child

Question	Answer*	References
<p>With which type of CP is the child diagnosed?</p>	<ul style="list-style-type: none"> <input type="radio"/> Spastic <input type="radio"/> Dyskinetic <input type="radio"/> Ataxic <input type="radio"/> Other... <input type="radio"/> Not classified 	<p>Bax et al. (2006) Rosenbaum et al. (2007)</p>
<p>What is the GMFCS level of the child?</p>	<ul style="list-style-type: none"> <input type="radio"/> I. Walks without limitations <input type="radio"/> II. Walks with limitations <input type="radio"/> III. Walks using a hand-held mobility device <input type="radio"/> IV. Self-mobility with limitations; may use powered mobility <input type="radio"/> V. Transported in a manual wheelchair 	<p>Geytenbeek et al. (2010) Himmelman et al. (2006) Odding et al. (2006)</p>
<p>How does the child communicate?</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Spoken language <input type="checkbox"/> Sound <input type="checkbox"/> Signing <input type="checkbox"/> Alternative communication (such as communication book) <input type="checkbox"/> Communication device 	<p>Existing survey</p>

	<p>with speech performance</p> <ul style="list-style-type: none"> <input type="checkbox"/> Other... 	
What is the frequency of epileptic seizures?	<ul style="list-style-type: none"> <input type="radio"/> Frequent seizures (very day or every week) <input type="radio"/> Infrequent seizures (less than every week) <input type="radio"/> Never 	<p>Meihuizen- De Regt et al. (2009)</p> <p>Voorman et al. (2006)</p> <p>Zafeiriou et al. (1999)</p>
Does the child use antiepileptic medication?	<ul style="list-style-type: none"> <input type="radio"/> Yes, namely.... <input type="radio"/> No 	<p>Voorman et al. (2006)</p> <p>Zafeiriou et al. (1999)</p>
Does the child use other medication than antiepileptic medication?	<ul style="list-style-type: none"> <input type="radio"/> Yes, namely... <input type="radio"/> No 	-
Has the medication of the child changed in the past year?	<ul style="list-style-type: none"> <input type="checkbox"/> Yes (describe which medication and the quantity of medication in the past and describe which medication and the quantity of the present medication) <input type="checkbox"/> No 	-
Which limitations or impairments occur in the child?	<ul style="list-style-type: none"> <input type="checkbox"/> Autism <input type="checkbox"/> Mental retardation, IQ < 70 <input type="checkbox"/> Delay in general development <input type="checkbox"/> Hearing impairment <input type="checkbox"/> Vision impairment <input type="checkbox"/> Problems with nutrition <input type="checkbox"/> Dysarthria <input type="checkbox"/> Anarthria 	<p>Existing survey</p> <p>Pirila et al. (2007)</p> <p>Voorman et al. (2010)</p> <p>Zafeiriou et al (1999)</p>

	<input type="checkbox"/> Motor apraxia <input type="checkbox"/> Other....	
Was the child hospitalized last year?	<input type="radio"/> Yes, because... <input type="radio"/> No	-
How many weeks was the child absent last year?	<input type="radio"/> One week <input type="radio"/> One to four weeks <input type="radio"/> Longer than four weeks	-
Which changes have occurred at home last year?	<input type="checkbox"/> Movement <input type="checkbox"/> Separation of parents <input type="checkbox"/> Birth of sibling <input type="checkbox"/> Bereavement in the family <input type="checkbox"/> Other... <input type="checkbox"/> No changes	-
Which changes have occurred at the education centre last year?	<input type="checkbox"/> Change of school or care institution (describe from which to which)... <input type="checkbox"/> New teacher <input type="checkbox"/> Illness of teacher <input type="checkbox"/> Change of class <input type="checkbox"/> Relocation of school <input type="checkbox"/> Other... <input type="checkbox"/> No changes	-

Speech and language therapy (Only when the child receives SLT)

Question	Answer*	References
What was the frequency of the individual speech	<input type="radio"/> Once per week <input type="radio"/> Twice per weeks <input type="radio"/> More than twice per	Cockerill (2011) Pennington et al. (2005)

and language therapy?	week	
What was the frequency of group therapy in speech and language?	<ul style="list-style-type: none"> <input type="radio"/> Once per week <input type="radio"/> Twice per week <input type="radio"/> More than twice per week <input type="radio"/> No group therapy 	-
Was there a change in the therapy frequency in the past year?	<ul style="list-style-type: none"> <input type="radio"/> Yes, the frequency is higher now <input type="radio"/> Yes, the frequency is lower now <input type="radio"/> No 	-
Which aims were stated?	<ul style="list-style-type: none"> <input type="checkbox"/> Speech <input type="checkbox"/> Expressive language <input type="checkbox"/> Receptive language <input type="checkbox"/> Development of conversation skills (such as questioning and solution of miscommunication) <input type="checkbox"/> Training of AAC <input type="checkbox"/> Nutrition <input type="checkbox"/> Other... 	<p>Cockerill (2011)</p> <p>Geytenbeek & Heim et al. (2010)</p> <p>Pennington et al. (2005)</p>

Final part

Question	Answer*	References
Additional comments		Existing survey

Thank you very much for participating.