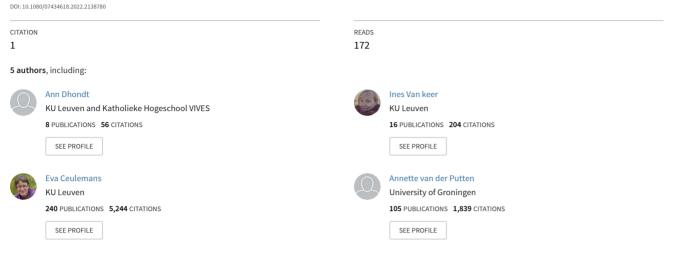
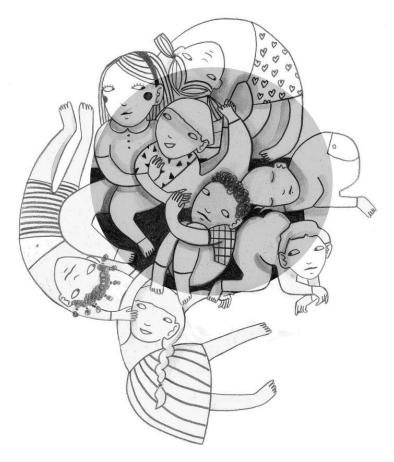
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Chapter 4

# Communicative Profiles of Young Children with a Significant Cognitive and Motor Developmental Delay

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#### Abstract

The communicative behavior of young children with significant cognitive and motor developmental delays is generally considered to be limited, idiosyncratic, and non-intentional. At present, changes between and within children over time regarding their communicative behavior are hard to detect. This paper describes an exploratory observational study that draws on data from the first data point of 38 children who are participating in a longitudinal project on the developmental trajectories of children with significant cognitive and motor developmental delays. The aims of the current study were to (a) describe the participants' communicative behavior in detail with communication-related variables that reflect differences across individuals, (b) create summarizing variables, and (c) explore whether subgroups of children can be detected. A self-developed coding scheme and descriptive statistics combined with correlational analyses were used, followed by a principal component analysis and visual inspection of the outcome of this analysis. The within-group differences related to communicative behavior was characterized using 16 variables. Based on these variables, three overarching components were formulated: Communication Proficiency, Expressions of Discomfort and Rejection, and Differentiation According to Focus. All participating children were found to be unique in terms of their component scores and the relationship among their component scores.

*Keywords:* Coding scheme; Communicative profiles; Early expressive communicative behaviors; Significant cognitive and motor developmental delays; Young children

# Describing the Communicative Profiles of Young Children with Significant Cognitive and Motor Development Delays

Research has demonstrated that, for children with typical development, the transition from pre-intentional to intentional communication is a crucial milestone for communicative development, indicating that individuals understand that they have an impact on others (Adamson et al., 2014; Bates et al., 1975; Crais & Ogletree, 2016; Perra & Gattis, 2012). This shift is preceded by consecutive stages in children's engagement states, intersubjectivity, and contingency awareness (Blain-Moraes & Chau, 2012; Salley et al., 2016; Trevarthen & Aitken, 2001). According to Wetherby and Prizant (1989), indicators for intentional communication are the use of alternating eye gaze (or any other conventional communication form) between the interaction partner and the goal, showing persistence in signaling and changing the quality of a signal until the goal is reached, terminating the signal when the goal is reached, and awaiting a response from the interaction partner and indicating (dis)satisfaction with this response. First, children with significant cognitive and motor developmental delays (referred to as profound and multiple disabilities in older children and adults) are generally believed to never (or only laboriously) reach the level of intentional communication (Nakken & Vlaskamp, 2007). Some researchers, however, suggest that, in these children, more atypical behaviors, such as persistence or anticipation, might indicate emerging intentionality (Brady et al., 2012; Bruce & Vargas, 2007; Carter & Iacono, 2002; Iacono et al., 1998). Second, they are described as displaying very limited and idiosyncratic communicative behaviors, such as facial expressions, body language, and early sounds (Granlund & Olsson, 1999; Stephenson & Dowrick, 2005). Third, these children are likely to show highly individual patterns of communicative

development, as development is impeded by the interaction of cognitive, motor, and frequently also sensory limitations (Bellamy et al., 2010; Houwen et al., 2016; Visser et al., 2017).

For caregivers, it is crucial to adapt intervention and communicative interaction to children's strengths and possibilities, regardless of whether the behavior is intentional or unintentional. As a result, all behavior should be valued as potentially communicative and responded to as such (Chadwick et al., 2019; Johnson et al., 2012); however, as previously noted, children with significant cognitive and motor developmental delays show idiosyncratic and limited communicative behaviors that are often very subtle and easy to overlook. Even if these children were to show intentional communicative behavior, chances are high that it would not be recognized as such because of the idiosyncratic nature of their communication (Atkin & Lorch, 2016; Bruce & Vargas, 2007; Carter & Iacono, 2002; Grove et al., 1999; Iacono et al., 1998; Keen et al., 2002; Sigafoos et al., 2000). Given the importance of the transition from preintentional to intentional communication for communicative development (Bates et al., 1975; Crais et al., 2004), knowledge of the early indicators of emerging intentionality is crucial, and detailed understanding of children's unique set of characteristics related to their specific communicative functioning is essential for this purpose (Goldbart et al., 2014). Existing instruments, however, are usually based on typically-developing children, use predefined behavioral categories, or do not address pre- and proto-symbolic stages (Brady et al., 2012; Chadwick et al., 2019; Dhondt et al., 2020). Using these instruments generally results in considering all children with significant cognitive and motor developmental delays to be part of the same group of pre-symbolic or pre-intentional communicators. Consequently, it is hard to detect or determine differences between these individuals, and changes over time are likely to go

unnoticed (Carnaby, 2007; Dhondt et al., 2020; Maes et al., 2021; Simmons & Watson, 2015; Wessels & van der Putten, 2017).

Some instruments specifically designed for individuals with complex communication needs suggest there are relevant parameters to evaluate early communicative behavior. The Communication Complexity Scale allows professionals to include both the used modalities and the orientation (single or dual focus) of the behavior in evaluating the communication complexity (Brady et al., 2012, 2018). A more pragmatic perspective on communicative behavior is used in the Communication Matrix, in which the communicative functions are evaluated in combination with the level and used modalities (Rowland, 2011). Different and important parameters of communicative performance can also be derived from previous research on both children who are typically developing and those children who are not. Described in the literature are, for example, communication rate (Brady et al., 2004; DeVeney et al., 2012; McLean et al., 1999) and communication levels from pre-symbolic and pre-intentional communicative behaviors to proper symbolic linguistic utterances (Dhondt et al., 2020; Rowland, 2011; Salley, 2020; Thiemann-Bourque et al., 2019). Similarly, in child development literature, progress in language pragmatics or functional communication is also described as the evolvement from idiosyncratic expressions to more conventional expressions with a clear communicative function (e.g., Adamson et al., 2014; Boundy et al., 2016; Brady et al., 2004; Bruce & Vargas, 2007; Carter & Iacono, 2002; Crais et al., 2009; Hostyn et al., 2011; Ogletree et al., 2012; Pepper, 2020; Perra & Gattis, 2010; Snell et al., 2010).

Furthermore, research shows that the type and the severity of disability in young children with developmental disabilities seem to be associated with specific engagement patterns. Hostyn and colleagues (2011) underline the role of attentional processes in interactions between persons

with profound intellectual and multiple disabilities and their interaction partners. Coordinated joint attention is assumed essential for the emergence of intentional communication. (Arens et al., 2005; Cress et al., 2007; Hostyn et al., 2011; Pepper, 2020). There is also some research on the use of specific modalities or communication forms in early communicative stages in both individuals with and without developmental delays.

The premise of the current study was that several communication-related parameters must be analyzed to obtain a differentiated view of the manifold facets of early communicative behavior of children with significant cognitive and motor developmental delays. This will enable differentiation between (groups of) individuals, and/or eventually permit researchers to describe changes over time. Given the challenge to differentiate among the children, the first aim of this study was to describe the communicative behavior of children with significant cognitive and motor developmental delays in detail by means of a variety of variables; however, making an estimation of individuals' communicative functioning based on a myriad of different variables is not particularly user-friendly. Therefore, the second aim was to explore some communicative components as overarching communication variables. These components should permit comparisons among participants, and eventually with themselves over time.

Finally, the third aim was to explore whether clusters of participants can be formed at the group level. Identification of subgroups would be desirable because the extent of customization in designing interventions could be reduced. Furthermore, subgroups would potentially facilitate the detection of inference of specific child characteristics or contextual aspects with communicative development over time; however, heterogeneity is expected in the specific target group of children with significant cognitive and motor developmental delays (Chadwick et al., 2019; Maes et al., 2020; Nakken & Vlaskamp, 2007; etc.).

The following research questions were addressed: (a) How can the communicative behavior of children with significant cognitive and motor developmental delays be described in detail to find within and between individual differences? (b) How can these variables be summarized in components resulting in communication profiles? (c) Can subgroups of participants with similar communicative profiles be created?

#### Method

This study is part of a longitudinal project examining the functioning of different developmental domains of young children with significant cognitive and motor developmental delays, conducted at the universities of Leuven and Groningen. The current study utilized the same participants, researchers, and data scheme as that of study by Dhondt et al. (2021), which analyzed early communicative behavior.

# **Participants**

The 38 participants met the following inclusion criteria: (a) were aged between 6 months and 59 months; (b) had significant cognitive delay characterized by a discrepancy between functional and chronological age with a ratio of 1 to 4 or less (functional age was defined by the Tandemlijst, a questionnaire used by professionals to estimate children's overall developmental age; Stadeus et al., 1994); and (c) had severe motor dysfunctions; that is, functioned at Level IV or V, or Level III for participants under the age of 24 months on the Gross Motor Function Classification System (Palisano et al., 1997). Participants were not excluded based on the cause of their delay or if they had additional challenges (e.g., visual impairment or hearing disorder). Per caregiver reports, all participants primarily functioned at a non-speaking, pre-symbolic, and non- or pre-intentional communication level. The majority (32) lived at home with their parents and attended special care facilities during weekdays; four lived full-time in a professional care facility, one lived at home part-time (3 to 4 days a week); and for one child this information was missing. Parents or legal representatives provided written informed consent for the children's participation. Table 1 presents detailed demographic information.

Insert Table 1 about here

## Setting

The study was conducted at the children's' respective homes.

# **Research Design**

The current study was an exploratory and descriptive observational study on the communicative behaviors of young children with significant cognitive and motor developmental delays. Video observations were coded by means of a self-developed coding scheme, and the data were quantitively analyzed. Ethical approval for the longitudinal project was obtained from the review boards of the Universities of Leuven and Groningen.

# Researchers

Data collection was undertaken by the first author and several researchers who were affiliated with research units at the universities of Leuven and Groningen. A strict protocol was followed. The first author delineated the behavioral units, coded all thick descriptions, and completed the data analysis. Two master students assisted as double coders.

#### Materials

As this study was part of a broader project on development of several developmental domains, an extensive test battery was used. During home visits that took about 3 to 4 hr, observations, tests, and questioning the primary caregiver (mostly the parent) were alternated to avoid children being overloaded. In case the children showed any signs of distress, observations and tests were interrupted and postponed to a later visit within two weeks. A questionnaire was used that included questions for caregivers regarding their children's vision, hearing, overall health, and residency.

Observational data was obtained by videotaping the participants with two Sony HDR-CX405 Handycams<sup>1</sup> on a tripod as they were engaged in three different sessions: (a) an adapted version of the Early Social Communication Scales (ESCS; Mundy et al., 2003), (b) the Behavior Appraisal Scales (BAS; Vlaskamp et al., 1999), and (c) a free-play situation. The ESCS is a videotaped standardized observation protocol conducted by a researcher unfamiliar to the participant to elicit early nonverbal communication skills; specifically, joint attention, behavioral requests, and social interaction (Mundy et al., 2003). The adapted protocol is available upon request and encompasses mainly an abridgement of the original protocol, motivated by the severity of the disabilities and the limited attention span of the target group. The procedure of the ESCS took on average 17 min 2 s per participant ( $SD = 5 \min 10$  s). The BAS is an observation in a semi-structured situation using different objects and actions to evaluate the participants' emotional communication, receptive language, general communicative behavior, visual behavior and explorative behavior, and admits support (practical and verbal) from a familiar person (Vlaskamp et al., 1999). Administration of the BAS was, on average, finished in 26 min 59 s (SD = 9 min 9 s). During the unstructured free-play interaction between the participant and a familiar caregiver, the caregiver was instructed to act and play according an interaction familiar to the participant. On average, the latter observation lasted for 12 min 47 s per participant (SD = 2 min 19 s). PP

# Procedures

## **Data Collection**

The existing coding scheme (Figure 1) was used to analyze data generated from the videos of each participant. First, potential communicative acts (PCAs) were marked with each change of behavior. A PCA is defined as "any observable change in the (idiosyncratic) behavior exhibited by the individual that might have a communicative purpose or that can be interpreted by communication partners as such" (Sigafoos et al., 2000, p. 79). This definition avoids the need for the behavior to comply with the criteria of a communicative act as defined by Prizant and Wetherby (1987), a mere change in behavior is ample to mark a PCA. Next, the PCAs were thickly described, a process that entailed a detailed description of child behavior, partner behavior and contextual aspects. In total, 6770 PCAs were detected in the 35 h 58 min and 12s of video recording.

# Insert Figure 1 about here

Once the PCAs were identified and described, the first author and master students coded descriptions in the following main coding categories and subcategories: (a) Context, with subcategories Setting and Task; (b) Partner Behavior, with subcategories Prompts and Scaffolding behavior; and (c) Child Behavior, with the subcategories Behavioral modalities, Focus, Initiative, Communication complexity, Signs of functionality (no codes, positive codes, and negative codes), and Signs of emerging intentionality (code and no code). The generated variables were the percentages of specific codes in the coding (sub)categories (e.g., percentage of negative codes in subcategory Signs of Functionality, indicating the participant indicates no) or derivates thereof (e.g., Person Predilection: percentage of PCAs in which focus is on person and the prompt is no person), except for the Communication Complexity related variable. Table 2

lists all included variables and the operationalization of each of the included variables, and includes a guide on how to interpret the variables.

Insert Table 2 about here

#### Data Analysis

Regarding the first research question, how to describe and identify differences in communicative behavior of children with developmental delays, the descriptive statistics of the variables (i.e., percentages of codes) were analyzed. Variables from the coding scheme were only included if visual inspection of the histograms and boxplots showed sufficient betweensubject variability. If two variables were closely related (i.e., a high Spearman's *r*), the variable with the largest dispersion (most variability) was chosen. For example, Mean Communication Complexity (the mean communication complexity score of the PCAs of the participant) and Maximal Communication Complexity (the average of the three highest communication complexity scores of their PCAs) were highly correlated (Spearman's Rho) but the dispersion was larger for Maximal Communication Complexity; therefore this was the selected variable. The same rationale was used regarding variables indicating the extent of focus on prompt for different foci and different prompts.

Related to the second research question, how to summarize communicative variables in components resulting in communication profiles, a principal component analysis was used to determine the principal components (no rotation, Kaiser-Meyer-Olkin Measure of Sampling Adequacy = .550, Bartlett's Test of Sphericity,  $\chi 2$ = 365.012, df = 120, *p* = <.01, extracting a few weighted sums of the original variables that explain as much variance as possible of the original data (Abdi & Williams, 2010). Based on the elbow of the scree plot, the decision was made to extract three components, which explained 57.9 % of the variance in the sample. The component

on which the variables showed the highest loadings was considered to be the primary component for that specific variable. Loadings are to be interpreted as the strength of the correlation of the variable with the component score (Pearson). The components and their variables were explored and labels or names were formulated for each of the three components.

Related to the third research question, can subgroups be determined based on communication profiles, the aim was to look for similarities between the participants and explore whether different clusters could be formed, based on their component scores. The component scores of the participants were plotted against each other and these plots were visually inspected. Finally, to illustrate the created component scores that determined the communication profile of the participants, three participants were selected, and their profiles were discussed while interpreting their scores on the different variables (see Appendix).

#### Reliability

The first author coded all participants. The master students involved in development of the existing coding scheme served as double coders. Five participants were coded by both master students. Codes were compared, differences were discussed, and final codes were consolidated (i.e., consensus coding). Next, each of the master students coded separately five different participants (twice n=5). In total, 15 of the 38 participants were double coded, corresponding with approximately 40% of the PCAs. Interrater agreement was calculated by the first author on the five participants for each master student (Rater A and Rater B) using Cohen's Kappa because of the categorical items on coding categories and level of codes as used in this study: Prompt (person, object, activity;  $\kappa A = .85$ ,  $\kappa B = .98$ ), Focus (person, object, activity, no focus;  $\kappa A = 84$ ,  $\kappa B = .97$ ), Signs of functionality (positive code/negative code/no code;  $\kappa A = .91$ ), all five behavioral

modalities (directed limb movements:  $\kappa A = .85$ ,  $\kappa B = .94$ ; visual behavior:  $\kappa A = 96$ ,  $\kappa B = .99$ ; early sounds:  $\kappa A = .97$ ,  $\kappa B = .1.00$ ; facial expressions:  $\kappa A = .98$ ,  $\kappa B = 1.00$ ) and Communication complexity ( $\kappa A = .81$ ,  $\kappa B = .98$ ).

## Results

Results are described in relation to the research questions: (a) describing the communicative behavior, (b) identifying the communicative components, and (c) clustering the participants.

# **Describing Communicative Behavior**

## Communication Rate, Communication, and Initiative

The communication rates of the participants ranged from .50 PCA per minute to 5.60 PCAs per minute (see Table 3). The Maximal Communication Complexity score (CCS) was seven or higher for 75% of the participants. According to Brady et al. (2012, 2018), this score corresponds with a dual focus and two or more potential communicative behaviors such as vocalizing, facial expression, a gesture, etc. of the Communication Complexity Scale. Participants showed initiative in none to approximately half of their PCAs. In this category, PCAs with an expression of discomfort with no focus, or a mere change in behavior with no expressed focus, were coded as initiated by the participant. Spearman correlation coefficients between these variables ranged from a moderate correlation of .34 (Communication Rate and Initiative) to a strong correlation of .62 (Communication Rate and Maximal Communication Complexity).

#### Insert Table 3 about here

# Aspects of Early Functionality and Emerging Intentionality

In 16% of the PCAs, the participants indicated "no" by either intentionally protesting, rejecting, or unintentionally showing discomfort without a focus (i.e., the negative codes). Dispersion of this variable, "indicating no," ranged from 0% to 41%. Both lower occurrences and lower dispersions were observed regarding (positive) Signs of Functionality and Signs of Emerging Intentionality. Signs of Functionality (positive codes) and Signs of Emerging Intentionality correlated significantly (Spearman's' r = .54); neither correlated with the variable, Indicating No.

# Modalities Used by Participants

Most of the participants showed visual behavior in a relatively high percentage of their PCAs, with a mean of 70% and a rather large standard deviation of 26%. All other modalities, early sounds, facial expressions, and directed limb movements, were coded with a more limited frequency, with concordant standard deviations. None of the modalities correlated highly, but there was a moderate correlation between Visual Behavior and Directed Limb Movements (Spearman's' r = .36).

# **Relationship Between Focus and Prompt**

Most of the participants showed a focus on prompt in the majority of their PCAs, with a mean score of 75% (Focus fits Prompt) and a relatively small standard deviation (16%). This indicates that the large range (36%-93%) was predominantly determined by outliers. The range of the second focus-prompt related variable, Person Predilection, was by far the largest of all variables (0%-100%), with a rather low mean (43%) and a relatively large standard deviation (23%). These two variables were moderately inversely correlated (Spearman's r = -.38).

## **Relationship Between Focus and used Modality**

The four variables that comprised the coding categories of focus and behavioral modality were named accordingly: Differentiation in Focus by using Visual Behavior, Directed Limb Movement, Early Sounds, or Facial Expressions. The descriptive characteristics (quartile scores, see Table 3) of three of these variables indicate that an equal number of participants used visual behavior, facial expressions and early sounds approximately to the same extent for persons and objects (median value or Q2 on and around .00). Ranges for these three variables on the negative side (i.e., using the modality more with focus on person) were much larger than ranges on the positive side (i.e., using the modality more with focus on object). Regarding Differentiation in focus by Directed Limb Movements, 75% of the participants used directed limb movements more in combination with a focus on objects than with a focus on persons (Quartile 1 = .03). None of these four variables correlated with each other.

#### **Identifying Communicative Components**

The factor analysis yielded three component scores onto which the variables loaded to different extents. These include communication proficiency, expression of discomfort and rejection, and differentiation according to focus (see Table 3).

#### Insert Table 3 about here

#### **Communication Proficiency**

Several variables contributed substantially to "communication proficiency" of the participant and included the following: the ease with which the communicative behavior was (a) detectable (Communication Rate, Maximal Communication Complexity, Visual Behavior, Directed Limb Movements), (b) interpretable (Signs of Functionality [positive codes] and Intentionality), (c) elicited (Focus on Prompt), (d) initiated (Initiative), and (e) differentiated between focus on object and person by using directed limb movements (Difference in Focus by the use of Directed Limb Movements). This was the component with the highest eigenvalue (4.82, corresponding with 30.14% of the variance in the sample).

# **Expressions of Discomfort and Rejection**

The second component (eigenvalue of 2.51, 15.70% of the variance) corresponded mainly with (a) Indicating No (negative codes in Signs of Functionality), (b) Initiative (also loading high on the first component), (c) Early Sounds, (d) Facial Expressions, and (e) inversely with Difference in Focus by using Early Sounds. This component related to expressions of rejection, protest, and discomfort, often elicited by inner distress stimuli, hence the high loading of the Initiative variable. Participants usually indicated "no" (expressing discomfort, or rejecting, or protesting) by using early sounds (whining, moaning, grunting, etc.) specifically towards persons; and facial expressions of Discomfort and Rejection by the participants. As can be seen in Table 3, loadings of Visual Behavior and Focus on Prompts were rather high and inversely correlated with this component; however, factor scores for these variables were related to the first component to a much higher extent.

#### **Differentiation According to Focus**

The third component explained 11.36% of the variance in the sample (eigenvalue = 1.70) and was predominantly presented by variables such as Person Predilection and Differentiation in Focus using Facial Expressions. Differentiation in Focus by using Visual Behaviors, however, showed a moderate correlation with this component. Differentiation in Focus by using Directed Limb Movements and Early Sounds was contributing to a lesser extent to this component. Signs of Functionality loaded negatively on this component; hence, this component was viewed as an

indicator of participant preference to focus on persons but at the same time using more modalities towards objects than towards persons when focusing on objects. This component was therefore labelled as Differentiation according to Focus.

# **Clustering Participants**

A graph indicating the three component scores per participant was created to visually explore the communicative profiles (see Figure 2). Communication Proficiency was the most decisive component in that it represented the most original variables and was responsible for most of the variability within the group. Therefore, participants were ranked according to their Communication Proficiency scores (the hatched zone in Figure 2) while their scores on Expressions of Discomfort and Rejection (the black bars in Figure 2) and Differentiation according to Focus (the grey flecked bars in Figure 2, respectively, were plotted against Communication Proficiency. The graph demonstrated that every participant showed a unique profile in how these three components were related to each other. In Appendix 1 an illustration of how the component scores helped to describe the communicative functioning of the participants is included.

#### Insert Figure 2 about here

#### Discussion

The first research question of the current study was to describe the communicative behavior of young children with significant cognitive and motor developmental delays in detail in order to detect potential within and between individual differences. A total of 16 communication-related variables were identified including the following: (a) Communication Rate, (b) Maximal Communication Complexity, (c) Initiative, (d) Signs of Emerging Functionality and Intentionality, (e) Indicating No, (f-g) two focus-related variables (Focus fits Prompt and Person Predilection), (h) Modalities used (Visual Behavior, Directed Limb Movements, Facial Expressions and Early Sounds) and (i) these four modalities in relation to the established focus (Differentiation in Focus by the using Specific Modality). These variables inter-correlated to varying degrees.

Regarding the second research question, these variables were reduced to three components: (a) Communication Proficiency, (b) Expressions of Discomfort and Rejection, and (c) Differentiation according to Focus. The most important component score to look at is Communication Proficiency because the scores for the other two components indicate more qualitative characteristics of the communicative performance. Finally, regarding the third research question, no subgroups could be identified based on the component scores, meaning that the participants were found to be unique in both the components scores as well as in the relation among these three scores. No clusters of similar participants could be formed.

Some considerations and nuances are to be made regarding these results. First, for some variables cross loadings were rather high on more than one component, indicating that those variables contributed to more than one component, although to a different extent. The component of Communication Proficiency was predominantly defined by the classic communicative measures, such as Communication Rate and Maximal Communication Complexity. In the group of children with significant cognitive and motor developmental delays, communication rate was, as expected, found to be rather low (Brady et al., 2004; DeVeney et al., 2012; McLean et al., 1999). The Maximal Communication Complexity, however (i.e., average of three highest scores as it is prescribed in Brady et al. (2012, 2018), was rather high with an average maximal complexity score of almost seven indicating a dual orientation and one potential communicative behavior. This finding contrasts with the Mean Communication Complexity (not included in the

16 selected variables due to a low dispersion) with an average score of almost three indicating only a single orientation and one potential communicative behavior (CCS; Brady et al., 2012, 2018). Furthermore, Signs of Functionality and Signs of Emerging Intentionality were expected to be quite limited within this population and to be linked to higher communicative levels (Bruce & Vargas, 2007; Pepper, 2020). The coding category Signs of Functionality was split into Indicating No (negative signs) and (Positive) Signs of Functionality as two separate variables. In the current study the occurrence of codes in Signs of Functionality and Signs of Emerging Intentionality was indeed quite low. These findings are consistent with the research of Hostyn and colleagues (2011). They demonstrated that joint attention (related to the triadic gaze as a prerequisite for intentional communication, cf. Brady et al., 2018) was present in persons with profound and multiple intellectual disabilities, but at very low frequencies.

Our findings pointed to a discrepancy between the utmost communicative functioning of the participants and their global communicative functioning indicating that most participants predominantly communicate in much less complex and pre-intentional ways. The fluctuating communicative complexity of the participants and the rather low frequencies of signs of functionality and signs of emerging intentionality indicate that the communicative performance of the participants might be influenced by the current engagement of the individual and several contextual and partner related factors. This is also suggested in research on engagement patterns in children with disabilities in structured and free play situations (Cress et al., 2007). Similar arguments regarding fluctuating performance were mentioned in research on alertness and multisensory environments in similar target groups (Munde et al., 2012; Ten Brug et al., 2015). Nevertheless, earlier research has indicated that there was no association on the level of the group between specific aspects of context or partner behavior and Signs of Emerging Intentionality (Dhondt et al., 2022). This suggests that the specific context or partner behavior characteristics responsible for these fluctuations are probably highly individual.

Our results showed that the variable Focus on Prompt is strongly connected with the first component, Communication Proficiency. The high scores on the Focus on Prompt variable indicate that this group of participants tended to focus on the presented prompts and let their interaction partners decide on the topic of the interaction. This can be labeled at most as passive joint engagement, developmentally situated after onlooking, person and object engagement, but before coordinated joint engagement (Perra & Gattis, 2012). Visual Behavior and Directed Limb Movements were also strongly anchored in the Communication Proficiency component indicating that children that can control their eye gaze and their upper limbs are largely privileged regarding their communicative proficiency. This finding contributes to the research of Houwen et al. (2016) on the interrelationship of motor control with cognitive and communicative development. Additionally, visual behavior is clearly the most frequently used modality, which corresponds with research in typically-developing children. Crais and Ogletree (2014) stated, for instance, that typically developing children increase their ability to communicate by first using eye-gaze, attending, and showing social-emotional affect and only later by adding gestures and other nonverbal means to communicate. Directed upper limb movements typically appear later in communicative development (Boundy et al., 2016; Brady et al., 2018; Rowland, 2011), and are evidently strongly influenced by motor impairments (Houwen et al., 2016). These findings endorse the assertion of the complex interplay of several developmental domains (Visser et al., 2017).

In the current study, the second component, Expressions of Discomfort and Rejection, was firmly connected with Indicating No, mostly expressed by Early Sounds (e.g., growling and grunting) and Facial Expressions (e.g., grimacing). Indicating No can be expressed by the participants by rejection and/or protest (against something or someone), but also by expressions of discomfort; hence the strong correlation with Initiative. Indicating No was predominantly coded as expression of discomfort, without displaying a focus (communication complexity score = 1) but rather as a reaction to an inner stimulus; therefore, this variable is probably to a lesser extent indicative for developmental growth. However, the more participants used early sounds towards persons instead of towards objects, the higher this component score is, indicating that these participants were more likely to appeal to the interaction partners during expression of their discomfort and rejection.

Finally, the third component, Differentiation according to Focus, must be considered in a specific way because of the connection with the Person Predilection variable. Some of the participants showed relatively high scores on Person Predilection, indicating that they were keen on focusing on a person, even if this person was not the presented prompt; however, this variable correlated inversely with Focus on Prompt, suggesting that participants who showed less focus on prompts, tended to show more person predilection. Controversially, this might also indicate that participants that were more inclined to focus on persons were less susceptible to a diversity of prompts for elicitation. Probably both statements are true; Person Predilection seemed to be connected both with lower and higher developmental stages. The reversed correlation with Signs of Functionality and Signs of Emerging Intentionality and the correlation with Differentiation in Focus by using Facial Expressions and other modalities indicates that this differentiation component will decrease over time. The assumption would then be that, in time, children will learn that particularly using facial expressions towards objects (the highest correlation with this component) does not contribute to the interaction. For interaction partners it is important to

recognize this and to adapt the interaction to promote and support the children's capacity to realize a greater degree of self-determination (Atkin & Lorch, 2016; Perra & Gattis, 2010).

Overall, regarding the relation of focus and used modalities, the results of the current study indicate that participants differentiated in used modalities according to the focus, with only directed limb movements clearly being used more for objects than for persons by most of the participants. The extent to which each of the participants used modalities more or less according to the focus, differed individually and was different for all modalities as well. This is not surprising given the interaction of the cognitive, motor and most often also sensory impairments influencing the engagement patterns of the participants (Bellamy et al., 2010; Ogletree et al., 2012).

Finally, taking the illustrations (see Appendix A) in consideration, the overall conclusion is that the component scores provide an overview of the overall communicative performance of the individual child. Nonetheless, inspecting the underlying variables of the components to comprehend and interpret the component scores remains an important aspect of evaluating their communicative behavior.

#### **Implications for Practice**

The added value of predominantly using the component scores lies in the simplicity of estimating an individual's communicative performance based on three scores; however, as indicated in the three illustrations, consulting the underlying variables is needed to interpret the component scores correctly. By plotting the component scores on separate graphs and adding the underlying variable scores, the communicative functioning of individuals over time can easily be made (visually) comprehensible and transparent to discuss progress. Related to the use of this coding scheme in clinical situations, it is important to note that using the coding scheme to

analyze extensive observations in a variety of settings is not feasible due to the heavy work-load of the coding process. Using the coding scheme in short video-fragments in specific settings however, seems more realistic. By meticulously reflecting on the components, the variables, and the relations intermutually and by comparing children's behavior in relation with partner behavior in different contexts, professionals will be challenged to really gain insight in the communicative behavior of the children in relation with the interaction partner and the context and to shape interventions and adapt these to the individuals' characteristics. Also, intervention outcomes can be evaluated and modified using this coding scheme. Particularly having team discussions about these outcomes will provide information that may contribute to the planning of the consecutive interventions. These discussions will offer professionals and caregivers a thorough insight on how different aspects influence the individual's communicative functioning and on how they can adapt their own behavior and the context to facilitate several communicative aspects. In this way, the coding scheme can easily be integrated in dynamic assessment procedures (Boers et al., 2013; Snell, 2002).

#### **Limitations and Future Directions**

A major limitation of research using this coding scheme at such a detailed level is that it is quite a laborious process. Even so, the amount of detailed information that is gained in this way is of tremendous value to obtain insight in the communicative behavior of these children with significant cognitive and motor developmental delays. Another important limitation is that parents or other familiar caregivers of the participants were not involved in the coding process. An unfamiliar researcher might miss some behaviors that are too small and therefore go unnoticed or are too idiosyncratic (Kruithof et al., 2020). According to other researchers in the field of persons with profound and multiple disabilities, however, it might methodologically be of an added value if coders are unfamiliar with the participants (Maes et al., 2020). Additionally, using video recordings reduces the chance that behaviors will be missed. Furthermore, all participants' videos are approached by the same researcher in the same way and coding itself showed high inter-rater agreement scores. Related to the partners' behavior, previous research on this data on the level of the group (all PCAs) pointed out that none of the modalities show a strong association with the presence or absence of scaffolding behavior of the partner. Only communication complexity and extent of focus on prompt differed significantly in PCAs with or without scaffolding behavior (Dhondt et al., 2022). Exploring this association on the level of the individuals was statistically too challenging as not all individuals were confronted with the same amount of and variety in scaffolding behaviors. Nevertheless, on the level of the individual cases, integrating these scaffolding behaviors and different settings in the process of evaluating the behaviors of the individual is highly recommended, particularly if the coding scheme is used for clinical purposes. Related to this is the unexpected lower score of some of the participants on visual behavior and the unexpected presence of visual behavior in children reported as having visual impairments by their parents. The cause for both these findings is probably two-fold: the rather high prevalence of visual impairment in this target group, known or unknown (Evenhuis et al., 2001; Van Splunder et al., 2006) and the fact that visual behavior is not always easy to detect in video observations (Atkin & Lorch, 2016). Additionally, refining the codes regarding the modalities would also deliver some more detailed information on the communicative functioning of the individuals, such as specifying directed limb movements in subcodes grasping, reaching, throwing, etc. Also, the ceasing of certain modalities could be interesting to integrate into the coding scheme. Particularly including these aspects in the discussion on the results of the coding scheme would be relevant on the level of the individual cases. Finally, variability as used in this

paper as a criterion to select the variables is a very relative concept, specifically because a sample size of 38 participants is generally esteemed as insufficient. The data of 38 children was used, all of whom belong to a target group known to be challenging in terms of assessment. Particularly in research on similar target groups small sample sizes are common (Maes et al., 2020). Related to the findings regarding the third research question about the unique patterns in how the components are related, a larger sample size is not likely to provide new information; however, following the sample by doing longitudinal research will yield new valuable information. Accordingly, future research should focus predominantly on how variables and the components change over time and whether specific characteristics of the participants, such as motor impairment, health issues, or age, are related to these changes over time and are predictive for progressing and making the transition to intentional communication. Additionally, also regarding partner related variables or contextual aspects, the association with the change in communicative functioning is relevant to explore.

#### Conclusion

Although the communicative behavior of young children with significant cognitive and motor developmental delays is generally considered to be limited, idiosyncratic, and nonintentional, this study revealed several aspects related to the communicative functioning of these children that differentiate individuals. These aspects can be summarized in three unrelated components that help to describe the communicative performance of these children. Both the detailed variables and the component scores contribute to a deep insight about several aspects of the early communicative functioning of children with significant cognitive and motor developmental delays and how these relate to each other and to aspects of the partners' behavior and the context. This paper offers a multi-dimensional perspective on the early communicative behavior of young children with significant cognitive and motor developmental delays.

All participating children were found to be unique in both their component scores as well as in the relation of their component scores. This highlights the importance of designing custommade communicative interventions, adapted to the individuals' strengths and weaknesses. Using the coding scheme of Dhondt et al. (2021) as part of intervention planning might help professionals in doing so.

#### References

- Abdi, H., & Williams, L. J. (2010). Principal component analysis. *Wiley interdisciplinary reviews: Computational statistics*, 2(4), 433-459. https://doi.org/10.1002/wics.101
- Adamson, L. B., Bakeman, R., Deckner, D. F., & Nelson, P. B. (2014). From interactions to conversations: The development of joint engagement during early childhood. *Child development*, 85(3), 941-955. https://doi.org/10.1111/cdev.12189
- Arens, K., Cress, C. J., & Marvin, C. A. (2005). Gaze-shift patterns of young children with developmental disabilities who are at risk for being nonspeaking. *Education and Training in Developmental Disabilities*, 158-170. https://doi.org/jstor.org/stable/23880088
- Atkin, K., & Lorch, M. P. (2016). An ecological method for the sampling of nonverbal signalling behaviours of young children with profound and multiple learning disabilities. *Developmental Neurorehabilitation*, 19(4), 211-225.
  https://doi.org/10.3109/17518423.2014.935822
- Bates, E., Camaioni, L., & Volterra, V. (1975). The acquisition of performatives prior to speech. *Merrill-Palmer Quarterly of Behavior and Development, 21*(3), 205-226.
- Bellamy, G., Croot, L., Bush, A., Berry, H., & Smith, A. (2010). A study to define: profound and multiple learning disabilities (PMLD). *Journal of Intellectual Disabilities*, 14(3), 221-235. https://doi.org/10.1177/1744629510386290

Blain-Moraes, S., & Chau, T. (2012). Challenges of developing communicative interaction in individuals with congenital profound intellectual and multiple disabilities. *Journal of Intellectual and Developmental Disability*, 37(4), 348-359.
 https://doi.org/10.3109/13668250.2012.721879

- Boers, E., Janssen, M. J., Minnaert, A. E., & Ruijssenaars, W. A. (2013). The application of dynamic assessment in people communicating at a prelinguistic level: A descriptive review of the literature. *International Journal of Disability, Development and Education,* 60(2), 119-145. https://doi.org/10.1080/1034912X.2013.786564
- Boundy, L., Cameron-Faulkner, T., & Theakston, A. (2016). Exploring early communicative behaviours: A fine-grained analysis of infant shows and gives. *Infant Behavior and Development, 44,* 86-97. https://doi.org/10.1016/j.infbeh.2016.06.005
- Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D.,
  Romski, M.A., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., &
  Wilkinson, K. (2016). Communication services and supports for individuals with severe
  disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, *121*(2), 121-138. https://doi.org/10.1352/1944-7558121.2.121
- Brady, N. C., Fleming, K., Romine, R. S., Holbrook, A., Muller, K., & Kasari, C. (2018).
  Concurrent validity and reliability for the Communication Complexity Scale. *American Journal of Speech-Language Pathology*, 27(1), 237-246.
  https://doi.org/10.1044/2017 AJSLP-17-0106
- Brady, N. C., Fleming, K., Thiemann-Bourque, K., Olswang, L., Dowden, P., Saunders, M. D.,
  & Marquis, J. (2012). Development of the communication complexity scale. *American Journal of Speech-Language Pathology*, 21(1), 16–28. https://doi.org/10.1044/1058-0360(2011/10-0099)
- Brady, N. C., Marquis, J., Fleming, K., & McLean, L. (2004). Prelinguistic predictors of language growth in children with developmental disabilities *Journal of Speech*,

*Language, and Hearing Research, 47*(3), 663-677. https://doi.org/10.1044/1092-4388(2004/051)

- Bruce, S. M., & Vargas, C. (2007). Intentional communication acts expressed by children with severe disabilities in high-rate contexts. *Augmentative and Alternative Communication*, 23(4), 300-311. https://doi.org/10.1080/07434610601179960
- Carnaby, S. (2007). Developing good practice in the clinical assessment of people with profound intellectual disabilities and multiple impairment. *Journal of Policy and Practice in Intellectual Disabilities*, 4(2), 88-96. https://doi.org/10.1111/j.1741-1130.2007.00105
- Carter, M., & Iacono, T. (2002). Professional judgments of the intentionality of communicative acts. Augmentative and Alternative Communication, 18(3), 177-191. https://doi.org/10.1080/07434610212331281261
- Chadwick, D., Buell, S., & Goldbart, J. (2019). Approaches to communication assessment with children and adults with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*(2), 336-358. 10.1111/jar.12530
- Crais, E. R., Watson, L. R., & Baranek, G. T. (2009). Use of gesture development in profiling children's prelinguistic communication skills. *American Journal of Speech-Language Pathology*, 18(1), 95-108. https://doi.org/10.1044/1058-0360(2008/07-0041)
- Crais, E., & Ogletree, B. T. (2016). Prelinguistic communication development. In D. Keen, H.
  Meadan, N.C. Brady, & J.W. Halle, (Eds.), *Prelinguistic and minimally verbal communicators on the autism spectrum* (pp. 9-32). Springer. https://doi.org/10.1007/978-981-10-0713-2
- Cress, C. J., Arens, K. B., & Zajicek, A. K. (2007). Comparison of engagement patterns of young children with developmental disabilities between structured and free play. *Education and*

Training in Developmental Disabilities, 152-164. https://doi.org/jstor.org/stable/23879992

- DeVeney, S. L., Hoffman, L., & Cress, C. J. (2012). Communication-based assessment of developmental age for young children with developmental disabilities. *Journal of Speech, Language, and Hearing Research, 55*(3), 695-709. https://doi.org/10.1044/1092-4388(2011/10-0148)
- Dhondt, A., Van keer, I., van der Putten, A., & Maes, B. (2020). Communicative abilities in young children with a significant cognitive and motor developmental delay. *Journal of Applied Research in Intellectual Disabilities*, 33(3), 529-541.
  https://doi.org/10.1111/jar.12695
- Dhondt, A., Van keer, I., van der Putten, A., & Maes, B. (2021). In search of a novel way to analyze early communicative behavior. *Augmentative and Alternative Communication*, 37(2), 87-101. https://doi.org/10.1080/07434618.2021.1928283
- Dhondt, A., Van keer, I., Van der Putten, A., & Maes, B. (2022). Analysis of early expressive communicative behaviour of young children with significant cognitive and motor developmental delays. *British Journal of Learning Disabilities*, 0-0. https://doi.org/10.1111/bld.12440
- Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45(5), 457-464. https://doi.org/10.1046/j.1365-2788.2001.00350
- Goldbart, J., Chadwick, D., & Buell, S. (2014). Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning

disability. International Journal of Language & Communication Disorders, 49(6), 687-701. https://doi.org/10.1111/1460-6984.12098

Granlund, M., & Olsson, C. (1999). Efficacy of communication intervention for pre-symbolic communicators. *Augmentative and Alternative Communication*, 15(1), 25-37. https://doi.org/10.1080/07434619912331278545

Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 12(3), 190-203. https://doi.org/10.1111/j.1468-3148.1999.tb00076

- Hostyn, I., Neerinckx, H., & Maes, B. (2011). Attentional processes in interactions between people with profound intellectual and multiple disabilities and direct support staff. *Research in Developmental Disabilities*, 32(2), 491-503.
  https://doi.org/10.1016/j.ridd.2010.12.034
- Houwen, S., Visser, L., van der Putten, A., & Vlaskamp, C. (2016). The interrelationships between motor, cognitive, and language development in children with and without intellectual and developmental disabilities. *Research in Developmental Disabilities*, 53, 19-31. https://doi.org/10.1016/j.ridd.2016.01.012
- Iacono, T., Carter, M., & Hook, J. (1998). Identification of intentional communication in students with severe and multiple disabilities. *Augmentative and Alternative Communication*, 14(2), 102-114. https://doi.org/10.1080/07434619812331278246
- Johnson, H., Watson, J., Iacono, T., Bloomberg, K., & West, D. (2012). Assessing communication in people with severe-profound disabilities: Co-constructing competence. *Journal of Clinical Practice in Speech-Language Pathology*, 14(2), 64-68.

- Keen, D., Woodyatt, G., & Sigafoos, J. (2002). Verifying teacher perceptions of the potential communicative acts of children with autism. *Communication Disorders Quarterly*, 23(3), 131-140. https://doi.org/10.1177/15257401020230030201
- Kruithof, K., Willems, D., van Etten-Jamaludin, F., & Olsman, E. (2020). Parents' knowledge of their child with profound intellectual and multiple disabilities: An interpretative synthesis. *Journal of Applied Research in Intellectual Disabilities*, *33*(6), 1141-1150. https://doi.org/10.1111/jar.12740
- Maes, B., Nijs, S., Vandesande, S., Van Keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J.,
  Petitpierre, G., & Van der Putten, A. (2021). Looking back, looking forward:
  Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, *34*(1), 250-262. https://doi.org/10.1111/jar.12803
- McLean, L. K., Brady, N. C., McLean, J. E., & Behrens, G. A. (1999). Communication forms and functions of children and adults with severe mental retardation in community and institutional settings. *Journal of Speech, Language, and Hearing Research, 42*(1), 231-240. https://doi.org/10.1044/jslhr.4201.231
- Munde, V., Vlaskamp, C., Post, W. J., Ruijssenaars, A. J. J. M., Maes, B., & Nakken, H. (2012).
  Observing and influencing alertness in individuals with profound intellectual and multiple disabilities in multisensory environments. *Journal of Cognitive Education and Psychology*, *11*(1), 5. DOI: 10.1891/1945-8959.11.1.5
- Mundy, P., Delgado, C., Block, J., Venezia, M., Hogan, A., & Seibert, J. (2003). Early social communication scales (ESCS) [Manual]. Coral Gables, FL: University of Miami.

- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in intellectual Disabilities*, 4(2), 83-87. <u>https://doi.org/10.1111/j.1741-1130.2007.00104</u>
- Ogletree, B. T., Davis, P., Hambrecht, G., & Phillips, E. W. (2012). Using milieu training to promote photograph exchange for a young child with autism. *Focus on Autism and Other Developmental Disabilities*, 27(2), 93–101. <u>https://doi.org/10.1177/1088357612441968</u>
- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997).
  Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology*, *39*(4), 214-223.
  https://doi.org/10.1111/j.1469-8749.1997.tb07414
- Pepper, L. (2020). Assessing pre-linguistic communication in young people with profound intellectual and multiple disabilities (PIMD). University College London. [Unpublished Doctoral dissertation] https://discovery.ucl.ac.uk/id/eprint/10097137/
- Perra, O., & Gattis, M. (2010). The control of social attention from 1 to 4 months. *British Journal of Developmental Psychology*, 28(4), 891-908.

https://doi.org/10.1348/026151010X487014

Perra, O., & Gattis, M. (2012). Attention engagement in early infancy. *Infant behavior and development*, 35(4), 635-644. <u>https://doi.org/10.1016/j.infbeh.2012.06.004</u>

Prizant, B. M., & Wetherby, A. M. (1987). Communicative intent: A framework for understanding social-communicative behavior in autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 26, 472–479. doi:10.1097/00004583-198707000-00002

- Rowland, C. (2011). Using the communication matrix to assess expressive skills in early communicators. *Communication Disorders Quarterly*, 32(3), 190-201. https://doi.org/10.1177/1525740110394651
- Salley, B., Brady, N. C., Hoffman, L., & Fleming, K. (2020). Preverbal communication complexity in infants. *Infancy*, 25(1), 4-21. https://doi.org/10.1111/infa.12318
- Salley, B., Sheinkopf, S. J., Neal-Beevers, A. R., Tenenbaum, E. J., Miller-Loncar, C. L., Tronick, E., Lagasse, L. L., Shankaran, S., Bada, H., Bauer, C., Whitaker, T., Hammond, J., & Lester, B. M. (2016). Infants' early visual attention and social engagement as developmental precursors to joint attention. *Developmental Psychology*, *52*(11), 1721. https://doi.org/10.1037/dev0000205
- Sigafoos, J., Woodyatt, G., Keen, D., Tait, K., Tucker, M., Roberts-Pennell, D., & Pittendreigh, N. (2000). Identifying potential communicative acts in children with developmental anphysical disabilities. *Communication Disorders Quarterly*, 21(2), 77-86. https://doi.org/10.1177/152574010002100202
- Simmons, B., & Watson, D. (2015). From individualism to co-construction and back again: Rethinking research methodology for children with profound and multiple learning disabilities. *Child Care in Practice*, 21(1), 50-66.

https://doi.org/10.1080/13575279.2014.976179

Snell, M. E., Brady, N., McLean, L., Ogletree, B. T., Siegel, E., Sylvester, L., Mineo, B., Paul, D., Romski, M. A., & Sevcik, R. (2010). Twenty years of communication intervention research with individuals who have severe intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *115*(5), 364–380. https://doi.org/10.1352/1944-7558-115-5.364

- Stadeus, A., Windey, K., Raman, M., Vermeir, G., & Van Driessche, S. (1994). Tandemlijst voor jonge kinderen met ontwikkelingsmoeilijkheden: Handboek voor de begeleider [Manual]. Maklu.
- Stephenson, J., & Dowrick, M. (2005). Parents' perspectives on the communication skills of their children with severe disabilities. *Journal of Intellectual and Developmental Disability*, 30(2), 75-85. https://doi.org/10.1080/13668250500125031
- Ten Brug, A., Van der Putten, A. A., Penne, A., Maes, B., & Vlaskamp, C. (2015). Factors influencing attentiveness of people with profound intellectual and multiple disabilities to multisensory storytelling. *Journal of Policy and Practice in Intellectual Disabilities*, *12*(3), 190-198. https://doi.org/doi.org/10.1111/jppi.12128
- Thiemann-Bourque, K. S., Brady, N., & Hoffman, L. (2019). Application of the communication complexity scale in peer and adult assessment contexts for preschoolers with autism spectrum disorders. *American Journal of Speech-Language Pathology, 28*(1), 29-42. https://doi.org/10.1044/2018 AJSLP-18-0054
- Trevarthen, C., & Aitken, K. J. (2001). Infant intersubjectivity: Research, theory, and clinical applications. *Journal of Child Psychology and Psychiatry*, 42(1), 3-48. 4. https://doi.org/https://doi.org/10.1111/1469-7610.00701
- Van Splunder, J. A. N. G., Stilma, J. S., Bernsen, R. M., & Evenhuis, H. M. (2006). Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: crosssectional study. *Eye*, 20(9), 1004-1010. https://doi.org/10.1038/sj.eye.6702059
- Visser, L., Vlaskamp, C., Emde, C., Ruiter, S. A., & Timmerman, M. E. (2017). Difference or delay? A comparison of Bayley-III Cognition item scores of young children with and

without developmental disabilities. *Research in Developmental Disabilities*, 71, 109-119. https://doi.org/10.1016/j.ridd.2017.09.022

- Vlaskamp, C., van der Meulen, B. F., & Smrkovsky, M. (1999). GedragsTaxatie-Instrument GTI: voor personen met ernstige meervoudige beperkingen [Manual]. Stichting Kinderstudies.
- Wessels, M. D., & van der Putten, A. A. (2017). Assessment in people with PIMD: Pilot study into the usability and content validity of the Inventory of the Personal Profile and Support. *Cogent Psychology*, 4, 1-10. <u>https://doi.org/10.1080/23311908.2017.1340082</u>
- Wetherby, A. M., & Prizant, B. M. (1989). The expression of communicative intent: Assessment guidelines. *Seminars in Speech and Language*, 10(1), 77-91. DOI: 10.1055/s-0028-1082491

End Notes

<sup>1</sup> Sony HDR-CX405 Handycams are a product of Sony Corporation, Tokyo, Japan

# Figure 1

Schematic Overview, Sample Coding Scheme

PARTNER BEHAVIOR		CHILD BEHAVIOR			
Prompt         Object         Person         Activity         Mix         CONTEXTUAL ASPECTS         Instrument         ESCS         BAS         Free play situation         Task         Social interaction         Object related         Book	Scaffolding behaviors Code No code	Focus No focus Object Person Activity Dual focusInitiativeInitiative $(CCS 2 - 4)$ Dual/triadic foc 	$\frac{Modalities}{Undirected}$ Undirected body/head Directed upper limb Visual behavior Sound/facial expressions $\frac{n \text{ complexity}}{1)}$ 0, 1, or 2 additional behaviors $cus + 0, 1, or 2 \text{ additional behaviors}$ $\frac{1}{1000}$		
Food Care Intermezzo		No Signs (Positive) sign Indicating no			

Characteristics		п	
Nationality	Belgium	18	
-	The Netherlands	20	
Sex	Male	16	
	Female	22	
Etiology	Acquired brain injury	3	
	Genetic defect	14	
	Perinatal asphyxia	2	
	Unknown	18	
	Missing data	1	
Vision-hearing	Good	11 - 27	
C	Quite good	4 - 4	
	Not so good	14 - 1	
	Blind/deaf	2 - 2	
	Unknown	2 - 1	
	Missing data	1 - 3	
Motor functioning <sup>a</sup>	<0.5	10	
-	0.5  to < 1	10	
	1 to < 1.5	8	
	$\geq 1.5$	5	
	Missing	2	
Additional health problems	Gastro-esophageal problems/digestion	18	
-	Cardiovascular problems	2	
	Respiratory problems	11	
	Epilepsy	23	
	Other health issues	15	

Table 1		
Participants' Demographics	(N = .	38)

*Note.* Information provided reflects caregiver views. Operational definitions of the categories were not determined. Participant ages ranged from 12.72 to 58.68 months, X=36.24; *SD*: 12.68; <sup>a</sup> Motor functioning is operationalized by the mean score on a questionnaire based on the motor questions of the Portage Program (range= .03-1.68; X=.89; *SD*= .5). The motor questionnaire consists of 145 items scored on a 3- point scale (0=not mastered; 1=almost mastered; 2= mastered). The lowest scores (between .00 and .50) correspond with individuals developing towards turning their head and obtaining some control over their upper limbs. The middle scores are indicative for individuals showing a development towards sitting independently for a short period of time and using upper limbs in a more controlled way (between .50 and 1.00) and individuals developing towards being able to move independently, standing with support and using their upper limbs in a more exploratory way (between 1.00 and 1.50). The highest scores correspond with individuals developing towards walking independently and using their upper limbs in a more functional way (between 1.50 and 2.00).

# Table 2

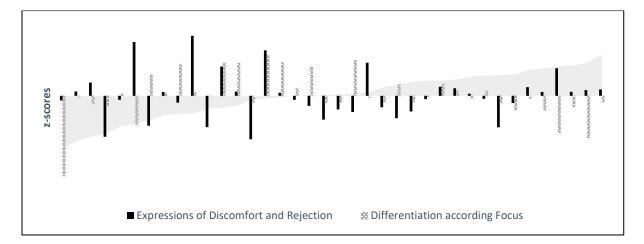
Definition and Operationalization of Variables

Variables	Definition	Operationalization			
Real rate	A measure for the real communication rate, with the exclusion of unintentional expressions of discomfort or other merely reflexive changes of behavior, expressed in PCAs/minute	The total amount of PCAs <sup>a</sup> with a communication complexity higher than 1 divided by the total duration of the three videos			
Optimal CCS	A measure for the maximum communication complexity the participant has shown over three observations (ESCS <sup>b</sup> , Free Play and BAS <sup>c</sup> ), ranging from one to twelve.	All PCAs received a Communication Complexity Score (CCS). The optimal CCS is the mean of the highest three CCSs of the participant (cf. Brady et al., 2018)			
Initiative	A measure reflecting the level of initiative of the participant (.00-1.00)	The percentage of PCAs not directly initiated by the interaction partner but initiated by the participant (or an inner stimulus)			
Indicating no	A measure for the expression of discomfort and discontentment (.00-1.00)	The percentage of PCAs in which the participant indicated no in some way (by a mere expression of discomfort, or by protesting or rejecting something)			
Sign of functionality	A measure for the (developing) functionality of the behavior of the participant (.00-1.00)	The percentage of PCAs in which the behavior of the participant was less idiosyncratic and assigning a function was self-evident, cf. Positive codes in coding scheme (e.g., attention drawing, showing affection, etc.) [masked for review]			
Sign of emerging intentionality	A measure for the emergent intentionality of the participant (.00-1.00)	The percentages of PCAs in which the behavior showed a characteristic of emerging intentionality, such as goal- directedness, persistence, satisfaction when goal is met, reciprocity, etc. [masked for review]			
Visual behavior	A measure for the use of visual behavior as a way of showing a focus	The percentage of PCAs in which visual behavior was coded			

Directed limb movements	A measure of the use of directed limb movement (e.g., reaching, taking, throwing, moving towards, etc.) as a way of showing a focus	The percentage of PCAs in which directed limb movements were coded
Early sounds	A measure of the use of early sounds as a way to express oneself (whether it is unintentional or intentional)	The percentage of PCAs in which early sounds were coded (grunting, humming, laughter, vocalizing, etc.)
Facial expressions	A measure of the use of facial expressions as a way to express oneself (whether it is unintentional or intentional)	The percentage of PCAs in which facial expressions were coded (e.g., grimacing, tension, smile, etc.)
Focus fits prompt	A measure for the extent to which the participant is engaged in the interaction as a result of actions of the interaction partner	The percentage of PCAs in which the focus of the participant was indeed on the prompt provided by the interaction partner
Person predilection	A measure for the extent to which the participant is person oriented or has a preference to focus on persons	The percentage of PCAs in which the focus of the participant is on a person, even if the interaction partner is prompting an object
Differentiation in focus by using visual behavior Differentiation in focus by using directed limb movements Difference in focus by using early sounds Difference in focus by using facial expressions	A measure for the use of the specific modality regarding the focus of the participant (the more negative = more in focus on person, the closer to zero = no difference, the more positive = more in focus on object)	The percentage of the specific modality in PCAs with focus on object minus the percentage of the specific modality in PCAs with focus on person (modalities are visual behavior, directed limb movements, early sounds, facial expressions)

Notes: a = Potential Communicative Acts; b = Early Social Communication Scales; c = Behavior Appraisal Scales;





Note. Participants on X-axis are ranked according to their Communication Proficiency scores

# Appendix A Meet (some of) the Participants

Table 1

Component and Variable Scores of Three Participants

Component scores and variables	Isaura (15) Mary (3		y (38)	38) Leon (3)		
Component scores and variables	raw scores (z-scores) and quartile scores					
Communicative proficiency	.50	Q2-Q3	-1.87	<q1< td=""><td>1.4</td><td>&gt;Q3</td></q1<>	1.4	>Q3
Maximal communication complexity	9.33	>Q3	3.33	<q1< td=""><td>10</td><td>&gt;Q3</td></q1<>	10	>Q3
Directed limb movements	.39	Q2-Q3	.19	Q1 -Q2	.57	>Q3
Signs of emerging intentionality	.06	Q2-Q3	.00	<q1< td=""><td>.19</td><td>&gt;Q3</td></q1<>	.19	>Q3
Communication rate	3.51	>Q3	.5	<q1< td=""><td>1.55</td><td><q1< td=""></q1<></td></q1<>	1.55	<q1< td=""></q1<>
Prompt fits focus	.86	>Q3	.59	<q1< td=""><td>.89</td><td>&gt;Q3</td></q1<>	.89	>Q3
Visual behavior	.89	>Q3	.16	<q1< td=""><td>.73</td><td>Q1- Q2</td></q1<>	.73	Q1- Q2
Differentiation in focus by using directed limb movements	.27	Q2 <q3< td=""><td>38</td><td><q1< td=""><td>.38</td><td>&gt;Q3</td></q1<></td></q3<>	38	<q1< td=""><td>.38</td><td>&gt;Q3</td></q1<>	.38	>Q3
Signs of functionality	.03	<q1< td=""><td>.17</td><td>&gt;Q3</td><td>.17</td><td>&gt;Q3</td></q1<>	.17	>Q3	.17	>Q3
Expressions of discomfort and rejection	75	<q1< td=""><td>.33</td><td>&gt;Q3</td><td>1.25</td><td>&gt;Q3</td></q1<>	.33	>Q3	1.25	>Q3
Indicating "no"	.07	<q1< td=""><td>.13</td><td>Q2-Q3</td><td>.30</td><td>&gt;Q3</td></q1<>	.13	Q2-Q3	.30	>Q3
Initiative	.22	<q2< td=""><td>.16</td><td><q1< td=""><td>.44</td><td>&gt;Q3</td></q1<></td></q2<>	.16	<q1< td=""><td>.44</td><td>&gt;Q3</td></q1<>	.44	>Q3
Early Sounds	.45	>Q3	.32	Q1-Q2	.54	>Q3
Facial expressions	.35	Q2-Q3	.23	Q1-Q2	.47	>Q3
Differentiation in focus by using early sound (inversely correlated)	02	Q2-Q3	.13	>Q3	05	Q1-Q2
Differentiation according focus	.03	Q1-Q2	-4.1	<q1< td=""><td>-1,20</td><td>&gt;Q3</td></q1<>	-1,20	>Q3
Differentiation in focus by using facial expressions	14	<q1< td=""><td>-1,00</td><td><q1< td=""><td>41</td><td><q1< td=""></q1<></td></q1<></td></q1<>	-1,00	<q1< td=""><td>41</td><td><q1< td=""></q1<></td></q1<>	41	<q1< td=""></q1<>
Person predilection	.24	<q1< td=""><td>.00</td><td><q1< td=""><td>.18</td><td><q1< td=""></q1<></td></q1<></td></q1<>	.00	<q1< td=""><td>.18</td><td><q1< td=""></q1<></td></q1<>	.18	<q1< td=""></q1<>
Differentiation in focus by using of visual behavior	.07	>Q3	75	<q1< td=""><td>.27</td><td>&gt;Q3</td></q1<>	.27	>Q3

To illustrate how the component scores together with the variable scores can help to interpret the communicative functioning of children with significant cognitive and motor developmental delays, three participants are described with a low, medium, and high score on the component of Communication Proficiency (Isaura Rank 15, Mary Rank 38, and Leon Rank 3). All scores, both variable and component, are relative to the other participants in the study, namely young children with significant cognitive and motor developmental delays.

Isaura (who is 3 years and 8 months) laughs and tenses her body when faced with new and exciting things, has no contingency awareness according to her mother, uses only non-verbal communication in a non-symbolic way and shows no clear signs of intentional communication.

She lives at home with her parents and siblings and attends specialized day-care. She obtains a score in the third quartile for the component of Communication Proficiency. For all the variables contributing to this component score, she is situated in the third and fourth quartile of the participants. A low percentage of Indicating No (<Q1) is observed, as well as a low percentage of initiated PCAs by herself (Initiative; Q1-Q2). She does use a lot of early sounds (Early Sounds; >Q3) and facial expressions (Facial Expressions; Q2-Q3). Overall, she is characterized by a rather low score for Expressions of Discomfort and Rejection, mostly defined by the low number of Indicating No (<Q1). Isaura differentiates moderately low between persons and objects (Differentiation according Focus; Q1-Q2) and shows a rather weak tendency to focus unprompted on persons (Person Predilection; <Q1). She does, however, use facial expressions less (Facial Expressions;<Q1) and directed limb movements more (Directed Limb Movements; >Q3) in combination with a focus on object compared to the other participants.

Mary is 13 months old. She lives with her mom, dad and older sister. Four days in a week she goes to a daycare center. She has little to no motor control in her body parts, is tube fed, mainly expresses comfort and discomfort in an unintentional way (grimaces, tension, grumping, vocalizing, etc.), and she is severely visually impaired. She also uses directed upper limb movements, but probably still not deliberately (dixit the mother). For most variables connected with the component of Communication Proficiency she scores in the first quartile as well as for the component itself. Only for Directed Limb Movements and Signs of Functionality, she has a higher score (resp. Q1-Q2 and >Q3). Regarding the component Expressions of Discomfort and Rejection, she obtains a high score (>Q3). She indicates 'no' quite often (Indicating No; Q2-Q3) and shows only little initiative (Initiative; <Q1). She scores moderately on Facial Expressions and Early Sounds and uses these early sounds more in combination with objects than in focusing on a person (Differentiation in Focus by using Early Sounds; >Q3). Important to note is that she is reported by her parents as having a visual impairment, hence the low percentage of Visual Behavior (<Q1). This variable shows a positive high loading on Communication Proficiency, but also a negative high loading on Expressions in Discomfort and Rejection, strengthening the negative score on this component score. Finally, she scores low on the third component, mainly because she never focuses on persons when not prompted (Person Predilection) and uses facial expressions and directed limb movements more in combination with a focus on person (Differentiation in Focus by using Facial Expressions and Directed Limb Movements). Moreover, based on inspection of all variables, one conclusion could be that she is hard to prompt, but if the interaction partner succeeds in engaging her, her focus will be most probably on the prompting person and she will use all four included modalities. In this specific case, the specificities in the component scores and the underlying variables are to be explained by the visual impairment of the participant.

Finally, there is Leon, a boy of 2;6 who lives with his parents, his older sister, a dog, and several cats; and attends a care facility during daytime. He is interested in new things and new persons, will explore his environment by looking, touching, manipulating, and shows a preference for certain materials over others. Sometimes he is frightened, such as when the curtains close, when routines alter suddenly, and for specific kinds of food (only recently tube feeding is being phased out). He can move independently by rolling over or turning over. He seeks contact with familiar people by reaching out. Leon has a relatively high Maximal Communication Complexity, shows Signs of Emerging Intentionality in almost 20% of his PCAs. The other variables related to the

component of Communication Proficiency score rather high, except for Visual Behavior and Communication Rate (lower scores). This might indicate that he communicates more efficiently (lower rate in combination with higher complexity). He also scores high on all the variables linked to the component of Expressions of Discomfort and Rejection, as well as on the component itself. Despite the high score on Early Sounds, he does not really make a difference with early sounds according to his focus (Differentiation in Focus by using Early Sounds). He does not tend to focus on persons (Person Predilection; <Q1) but makes much more difference with the use of facial expressions (more towards persons) and directed limb movements (more towards objects) than many of the other participants (Differentiation in Focus by using Facial Expressions and Directed Limb Movements). This boy could be carefully considered as objectdirected in his visual behavior, and if he focusses on a person, it is mainly to protest or to reject something (high in Indicating No and Initiative).