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Can I be your safe haven and secure base? A parental perspective on parent-child attachment in young children with a severe or profound intellectual disability

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ABSTRACT

Background: The general developmental as well as the disability specific literature has stressed the crucial influence of parents on their child's social-emotional development. Attachment theory provides a framework to describe parental roles within the parent-child attachment relationship. The current study explored parents' perspectives on their role as attachment figure and the preconditions they consider necessary to establish secure attachment in children with severe or profound intellectual disability (ID).

Methods: Semi-structured interviews with 54 parents on their child's social-emotional development, attachment behaviour and the parent-child attachment bond were analysed using the Framework Method. All children were between 15 months and seven years old and had a severe or profound ID.

Results: Parents reported their child's clear preference towards them and acknowledged the role they fulfil as stress regulator. Children differed in the extent to which they use their parent to explore new environments. Overall, parents described the attachment relationship with their child as positive but challenging.

Conclusions: Parents acknowledged the roles they fulfil both as a safe haven for their child, and (to a lesser extent) as a secure base. Clinical practice could benefit from a parental perspective to identify particular challenges parents encounter in building a secure attachment relationship.

What this paper adds

Despite the extensive amount of attachment research in typically developing children, the attachment relationship between parents and their child with a severe or profound ID has received little attention. However, the high prevalence of behavioural and mental health problems in persons with severe disabilities stresses the importance of attachment research, since attachment development defines the developing affect regulatory system. More particularly, the current study addresses the lack of a qualitative insight in parents' views on the parent-child attachment bond. Parents' perspectives, for instance on their role as attachment figures, play a major role in developing a relationship with their child. This exploratory study could help clinical practice to identify and eventually intervene in challenges parents encounter in developing a secure emotional bond with their child.

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1. Introduction

A child's development is strongly influenced by parents and their parenting behaviour (Belsky, 1984; Bronfenbrenner, 1994, 1979; Guralnick, 1998, 2006, 2011; Mahoney & Nam, 2011; Sameroff, 2009, 2010). Both in parenting research on typically developing children and in the disability specific parenting literature (e.g., Kurani, Nerurka, Miranda, Jawadwala, & Prabhulkar, 2009; Van Hooste & Maes, 2003), the crucial role of parents as primary agents in the (mal)adaptive functioning of their child is agreed upon. In line with this view, Guralnick's (1998, 2011) "developmental systems perspective" shows the crucial influence of family interaction patterns on the social and cognitive competences of children with disabilities. One of these family patterns is the quality of parent-child transactions, which is defined as a "*series of relationship processes*" (Guralnick, 2011, p. 11). In this model, Guralnick (2011) underlines the importance of a sensitive, responsive and reciprocal interaction between parents and children, being one of the most proximal and influential settings in which the child develops (Bronfenbrenner, 1986; Guralnick, 2006). However, among children with severe or profound intellectual disabilities (ID), parents' perspectives on these parent-child relationship processes remain largely unknown (Mahoney & Nam, 2011; Van keer & Maes, 2016).

Attachment theory is a valuable framework to describe the parent-child relationship, since the development-enhancing parent-child transactions described by Guralnick (2006) actually underlie the development of attachment bonds and vice-versa (Bowlby, 1969/1982; Cassidy, 2016; Guralnick, 2006). Therefore, the current study explored parents' perspectives on their role as an attachment figure and the preconditions they consider necessary to establish secure attachment with their child with a severe or profound ID. Attachment theory describes parent-child attachment as a long lasting, persistent and emotionally significant tie between a child and his/her parent as primary caregiver (Ainsworth & Wittig, 1969; Bowlby, 1969/1982; Cassidy, 2016). This affectional relationship serves as a context of comfort, especially during distress (Ainsworth, 1989; Cassidy, 2016). Accumulating experiences of care will, in turn, promote the child's feeling of trust and positive emotion (Ainsworth, 1979; Bowlby, 1969/1982). Young children are securely attached to their parent, when the parent fulfils the role of secure base and safe haven for the child (Ainsworth, 1979; Powell, Cooper, Hoffman, & Marvin, 2013). Whereas the parent as *secure base* supports the child in exploring the world, the parent as *safe haven* helps the child to regulate his/her affect in times of distress or in dealing with emotions, possibly engendered in the process of exploration, by sensitively reacting to their child's emotional cues (Ainsworth, Blehar, Waters, & Wall, 1978; Atkinson et al., 1999; Bowlby, 1969; Cassidy, 1994). In contrast, where parental sensitivity is unpredictable, unstable or absent, children tend to develop insecure attachment patterns such as avoidance, ambivalence and disorganisation (Ainsworth et al., 1978; Atkinson et al., 1999; Bowlby, 1969/1982; Main & Solomon, 1990). The child's experience of the extent to which the parent adequately and consistently fulfils the role of secure base and safe haven, eventually defines his/her own developing affect regulatory system (Bowlby, 1969; Mikulincer, Shaver, & Pereg, 2003). Affect regulation constitutes an important component of a child's social-emotional development (Claes & Verduyn, 2012).

In children with severe or profound ID, the body of literature on parent-child attachment is still limited. It is remarkable, however, that these children do seem to have a heightened likelihood for developing insecure attachment relationships (Atkinson et al., 1999; Howe, 2006; Schuengel & Janssen, 2006). Various explanations for this risk are proposed (Howe, 2006; Schuengel & Janssen, 2006), such as the child's idiosyncratic signals which impede the parents' sensitivity (Moran, Pederson, Pettit, & Krupka, 1992; Schuengel, Kef, Damen, & Worm, 2010), parents' prolonged distress and unresolved reactions towards their child's diagnosis (Feniger-Schaal & Oppenheim, 2013; Marvin & Pianta, 1996) or frequent hospitalisation in early childhood (Howe, 2006). In addition, besides these vulnerabilities related both to the parent and the child, it could be argued that there is, until now, a lack of reliable and valid instruments to measure attachment behaviour and quality in children with severe disabilities (e.g., Blacher, 1984; Cicchetti & Serafica, 1981; Thompson, Cicchetti, Lamb, & Malkin, 1985; Vandesande, Bosmans, Schuengel, & Maes, 2019).

Over the long tradition of attachment research in typically developing children, various methods (e.g., observation, questionnaires, narrative techniques and interviews) have been developed to validly and reliably measure attachment quality (Bosmans & Kerns, 2015). Examples of frequently used instruments are: the Strange Situation Procedure (Ainsworth et al., 1978), Story Stems (Bretherton, Ridgeway, & Cassidy, 1990), the Security Scale (Kerns, Klepac, & Cole, 1996), the Child Attachment Interview (Borelli et al., 2010) and the Secure Base Script test (Psouni & Apetroaia, 2014; Waters, Bosmans, Vandevivere, Dujardin, & Waters, 2015). However, children with severe or profound ID have a significant cognitive delay (IQ $<$ 40; Kraijer & Plas, 2007), often accompanied by (neuro)motor and/or sensory dysfunctions (Nakken & Vlaskamp, 2007) and (very) limited (symbolic) communicative abilities (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007). Due to their specific characteristics, most of the typically used measures are not applicable in this target group.

Therefore, the current study describes parents' perspectives as one possible way to shed light on parent-child attachment in children with severe or profound ID. After all, parents' perspectives (such as their attitudes and perceptions) are known to play a major role in the relationship processes which influence a child's development (2011, Guralnick, 2006; Papoušek & Papoušek, 2002; Van Hooste & Maes, 2003). Moreover, parents' beliefs with regard to the parent-child relationship directly influence their parenting behaviour and the general parenting quality (Simons, Beaman, Conger, & Chao, 1993). In the field of attachment, Bretherton and colleagues (Bretherton, Biringen, Ridgeway, Maslin, & Sherman, 2006) also reported on significant associations between parents' interviews on parent-child attachment and other measures of attachment quality. These research findings nurture the belief that exploring parents' perspectives could prove useful to study parent-child attachment in this population.

Therefore, in the current study, we investigated the following research question: "What are parents' perspectives on the

relationship with their child with a severe or profound intellectual disability (ID)[1] ?" More specifically, the current study explored the following issues:

1 The *role* parents ascribe themselves as attachment figure (in terms of *safe haven* and *secure base*)
2 The *preconditions* they consider necessary to build a secure attachment bond with their child and how parents perceive this bond

2. Method

2.1. Participants

Participants were recruited from two different ongoing research projects, namely the OJKO[2] project and a study of Vandesande et al. (2019) on differentiated attachment behaviour in children with severe or profound ID. In both samples, interviews were conducted with parents of young children with a severe or profound ID discussing their child's behaviour, social-emotional functioning and the parent-child relationship. In total, more than 80 care organisations (e.g., day care centres, home support services) were asked to invite parents for the interview. Their children had to meet the following inclusion criteria: (1) The child's age was between six months and seven years old, and (2) The child was diagnosed with a significant developmental or multiple delay, which is likely to persist lifelong (functioning at the level of a severe or profound ID). Variations in the presence and nature of their additional disabilities (e.g., visual or motor problems) were possible.

In total, 54 interviews were conducted with the mother (n = 32, 59.3%), the father (n = 4, 7.4%) or both (n = 18, 33.3%) as primary respondents. In the OJKO project, seven interviews were conducted with the child's professional caregiver. However, for the current study, only the interviews which were conducted with the parent were included. More than half of the interviews (n = 34) originated from the OJKO project, both in Belgium (n = 12) and the Netherlands (n = 22). The remainder (n = 20) were collected within the scope of a study on attachment behaviour in this population (Vandesande et al., 2019). Four families were multilingual, but every informant spoke Dutch/Flemish fluently. Child and parent characteristics of the sample are summarised in Table 1. All children communicated at pre- or protosymbolic level (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007), which was affirmed by the child's professional caregiver and confirmed by the researcher's clinical observation of video material.

2.2. Design and procedure

Semi-structured interviews with parents were conducted during a home visit, carried out by researchers holding a master's degree in Educational Sciences. The mean duration of the interviews was 41 minutes (ranging from 18m34s to 1h38m15s). All interviews conducted within the scope of the OJKO project and the study of Vandesande et al. (2019) were combined in the current study.

The OJKO project comprised a longitudinal study over a two years duration with six monthly administrations. Data were collected by means of one or two visits for each assessment point (either at home or in the care organisation). At each administration point, an extensive assessment battery with regard to the child's general, motor, communicative and social-emotional development, and several contextual factors, was administered. The battery included observations, questionnaires and tests. The interview, which is the source of information for the current study, involved the Social Emotional Developmental Scale- Revised (SEO-R; Claes & Verduyn, 2012) and took place at the first assessment point.

Data collection in the study of Vandesande et al. (2019) was obtained by means of a single home visit[3] . The visit consisted of several questionnaires, a semi-structured observation and was ended with a semi-structured interview. This interview concerned the child's (attachment) behaviour and the parent-child relationship in general and questions or topics were selected from both the SEO-R and the Disturbances of Attachment Interview (DAI; Smyke & Zeanah, 1999).

The Social and Societal Ethics Committee (SMEC, KU Leuven) granted ethical approval for both research projects (S56510, G-2015 06 258). Informed consent was obtained from the parents.

2.3. Instruments

The Social Emotional Developmental Scale – Revised (SEO-R, Claes & Verduyn, 2012) was administered to the parents, participating in the OJKO project. By means of the SEO-R, parents were asked about the social-emotional development of their child on 13 different domains: (1) Handling your own body, (2) Dealing with emotionally important persons, (3) Perception of him-/herself in interaction with the environment, (4) Dealing with the changing environment/permanence of objects, (5) Fears, (6) Dealing with peers, (7) Dealing with material, (8) Communication, (9) Emotion differentiation, (10) Aggression regulation, (11) Scheduling free

[1] Children function at the level of a severe or profound ID (below half of their chronological age or IQ < 40; Kraijer & Plas, 2007). However, not all of them have (yet) received a diagnosis, since reliable IQ-tests and established norms are often lacking for young children functioning at the level of a severe or profound ID.

[2] The OJKO project comprises a longitudinal study on the (communicative, social-emotional and motor) development of young children with a serious cognitive and motor developmental delay in Belgium and the Netherlands.

[3] In total, data was collected by four researchers of the same research team. Three researchers (other than the first author) were involved in data collection of the OJKO project. The first author of the current article was responsible for data collection in the study of Vandesande et al. (2019).

Table 1
Child and parent characteristics of the sample (n = 54).

		n (%)	M (SD)	Min-Max
Parent characteristics				
Nationality mother	Belgian	30 (55.6)		
	Dutch	22 (40.7)		
	Other	2 (3.7)		
Nationality father	Belgian	29 (53.7)		
	Dutch	23 (42.6)		
	Other	2 (3.7)		
Age mother		52 [a] (96.3)	35.15 (4.20)	27.00 - 45.00
Age father		48 [a] (88.9)	37.54 (5.89)	26.00 - 54.00
Child characteristics				
Nationality	Belgian	30 (55.6)		
	Dutch	24 (44.4)		
	Other	0 (0.0)		
Gender	Boy	26 (48.1)		
	Girl	28 (51.9)		
Chronological age (months)		54 (100.0)	44.91 (15.90)	15.00 - 83.00
Developmental age (months)		14 [b] (25.9)	11.11 (3.43)	6.00 - 16.50
Average cognitive delay compared to chronological age (months)		14 [b] (25.9)	49.04 (16.90)	16.00 - 75.00
Additional impairments/problems	Motor	48 (88.9)		
	Epilepsy	34 (63.0)		
	Visual	22 (40.7)		
	Autism	6 (11.1)		
	Auditory	4 (7.4)		
GMFCS level [c]	Level 1-3	13 (25.9)		
	Level 4 [d]	11 (20.4)		
	Level 5 [d]	29 (53.7)		
Attend day care (≥ part time)		50 (92.6)		
Living situation	With both biological parents	49 (90.7)		
	With one biological parent	4 (7.4)		
	Adoptive parents	1 (1.9)		
Mother's firstborn		25 (46.3)		
Siblings (≥ 1)		41 (75.9)		

[a] Information about the parents' age was missing for two mothers (3.7%) and six (11.1%) fathers, because these parents were completely out of the picture for the child or because the parent did not report on the other parent.

[b] In case the administration of a test of cognitive functioning was more than one year ago, results were not included in this study. Especially for young children with the profoundest ID, test results were lacking because reliable IQ-tests and established norms are lacking at the very low end of the spectrum of intellectual functioning (Resing & Blok, 2002; Weis, 2014). Hence, the average cognitive level of 11 months is presumably an underestimation.

[c] Missing information about Gross Motor Function Classification (GMFCS) level for n = 1.

[d] Level 4 and 5 indicate a severe motor impairment (Palisano, Rosenbaum, Bartlett, & Livingston, 2007).

time/play development, (12) Moral development, and (13) Emotion regulation. The current study mainly focused on the parents' answers regarding the Domains 1, 2, 4, 8, 9, 10 and 13, because these gave insight in the role of parents as attachment figure. In response to the SEO-R questions, parents described safe haven or secure base behaviour of their child, since several items of the SEO-R are closely aligned with attachment theory (Došen, 1990; Sappok et al., 2016). For example, domain 2 includes key themes such as developing a preference, emotional hierarchy and getting a feeling of security from caregivers. These issues are also of particular interest from an attachment perspective.

Within the scope of the study of Vandesande et al. (2019), the interview guide was inspired by the Dutch translation (Oosterman & Schuengel, n.d.) of the Disturbances of Attachment Interview (DAI, Smyke & Zeanah, 1999) and the SEO-R (Claes & Verduyn, 2012). Each interview covered seven issues: (1) Distinction between adults (e.g., *"Who are the emotionally significant others for X?"*), (2) Interest in interaction (e.g., *"How does X interact with other people?"*), (3) Behaviour in stressful situations and reaction to comforting (e.g., *"Who and how can you comfort X?"*), (4) Social communication (e.g., *"Is there reciprocity in X's social interaction?"*), (5) Behaviour in an unknown environment (e.g., *"Does X seek proximity or contact in an unfamiliar environment?"*), (6) Interaction with strangers (e.g., *"Does X behave differently in interaction with strangers?"*), and (7) Perception of attachment bond and conditions (e.g., *"How would you describe your attachment bond with X?"*). A detailed interview guide can be provided by the first author upon request.

Interview data from both projects contained rich information on parents' perspectives about the parent-child relationship and the child's attachment behaviour, though each originating from their own specific research context (that is, the OJKO project and the study of Vandesande et al., 2019). While certain questions could be placed in a different domain of the interview guide across both research projects, the questions and themes itself were very similar across both projects (e.g., the question "*Who are emotionally significant others for X?*" was identical in both projects, but was placed in domain 2 of the SEO-R (used in OJKO) and in domain 1 in the interview guide of Vandesande et al. (2019)). The interviews from both projects were treated complementarily and were analysed

Table 2
Thematic framework.[a].

I. Parent as safe haven/ emotionally significant other	
	Preference person
	Hierarchy in preference
	Preference signals
	Parent as emotion/stress regulator
	Preference and hierarchy in comforting
	Reaction after separation and separation anxiety
	Emotional influence within relationship
II. Parent as secure base from which to explore	
	Reaction of the child to new environment and persons
	Role of parents in exploring new environments
	Role of parents in meeting new persons
III. Attachment bond and preconditions	
	Nature of attachment bond and evolution
	Learning to interpret child's signals and communication
	Process of grief and acceptance
	Giving the child (physical) attention, patience, being there
	Adaptation, making choices in function of the child
	Getting support (formal and informal)
	Making room for own leisure time

[a]The grey-coloured themes were eventually not reported separately upon in the current paper, since these themes were of less importance to the research questions or were not prominent in the interview transcripts as a whole. The key messages are, however, regularly integrated in the other paragraphs.

in the same manner, as is described in the current article.

2.4. Qualitative analysis

The Framework Method (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie & Spencer, 1994) was used in the current study to illuminate and give words to parents' perceptions with regard to their parent-child attachment bond. The analytical process of Framework Analysis follows five distinct, but interconnected stages. First, in the stage of familiarisation, the researcher gained an overview of all the original transcripts to look for key ideas and emergent, recurrent themes through immersion in the data. Second, a thematic framework was constructed by the research team which resulted in a set of codes to be applied to the interview transcripts. The set of codes mainly included deductive a-priori themes, emerging from the literature (e.g., '*parent as emotion regulator'*) and were complemented by inductive themes, emerging from the data (e.g., '*making time for the child*'). The set of codes was categorised in three main themes: 1) Parent as *safe haven*, 2) Parent as *secure base* and, 3) Attachment bond and *conditions* for attachment. These categories derived partially from a first reading of the main themes in the interviews and partially from the Circle of Security framework (Powell et al., 2013). In the third stage, indexing, the theoretic framework was systematically applied to the text fragments in NVIVO by annotating the text excerpts with a reference to the thematic framework. In the current study, indexing was done in two phases, by 1) dividing the original transcripts in the three main themes and then by 2) making reference to the subcategories within the three main themes. A list of the codes that were used, can be found in Table 2. Only text segments which matched the scope of this study were included in the data analysis. This means that parents' answers on questions that were part of the SEO-R, but did not address parent-child attachment (e.g., '*How does your child handle his/her own body?*'), were excluded from data analysis. Fourth, charts were constructed to get a feel for the data as a whole by summarising the key message with regard to each code per interview. This resulted in three charts or matrices (safe haven, secure base and conditions) with a summary of each theme per interview. Finally, the data was mapped and interpreted using the charts and guided by the research questions. The results were described in the current study and were supported by illustrative quotations from parents.

To heighten the trustworthiness or rigour of the current research, various strategies were adopted (Creswell, 2007; Lincoln & Guba, 1985). To ensure credibility of the findings, several peer debriefing sessions with co-researchers were organised to achieve consensual validation (Creswell, 2007; Eisner, 1991; Lincoln & Guba, 1985). Furthermore, to obtain dependability of the findings,

good-quality audiotapes and transcripts were used (Creswell, 2007; Ghesquière, Maes, & Vandenberghe, 2004). In addition, inter-coder agreement was established. Together with a co-researcher, each step of the coding process was checked to control for subjectivity and to reach consensus. First, the co-researcher double-coded 11 randomly selected interviews (six from the study of Vandesande et al. (2019), five from the OJKO-project) within the three main categories (safe haven, secure base and attachment bond/preconditions). In general, almost full agreement was reached in this step of double-coding, with exception from a small number of text excerpts for which consensus was achieved after discussion. These exceptions were mainly on the issues of interest for interaction with people in general, social communication and separation anxiety. However, where information could be lacking in the study's results, the first author read all these text excerpts again to ensure that results were complete. Second, the co-researcher double-coded the fragments of five interviews which were coded within the three main categories (for each main category five different interviews were randomly selected) with regard to the subcategories of the thematic framework. In general, almost full agreement was reached in this step of double-coding, except for some text excerpts which were coded in an additional category by the first author and not by the co-researcher. All differences were discussed and consensus was reached. In total, 27 interviews of 54 were included in the process of double-coding. To control for subjectivity post coding (charting and interpretation), an external audit session with the co-researcher was held to assess the product of the study (Creswell, 2007; Savin-Baden & Howell Major, 2013). By reading and thoroughly discussing all charts and the description of the study's results, the manuscript was fine-tuned. To ensure confirmability of the findings, the most striking quotes from parents were included to support the main themes (Creswell, 2007; Lincoln & Guba, 1985). Transferability of the results was supported by providing an overview table of relevant parent and child characteristics and by reporting on exceptions within themes (Creswell, 2007; Patton, 2002).

3. Results

The themes will be presented in turn and illustrated with parents' quotes (indicated by quotation marks).

3.1. As parent, I am a safe haven for my child

3.1.1. My child has a preference for close caregivers, especially for us as parents

Generally, parents reported that their child prefers certain people. Mother and father were the most frequently mentioned preferred persons, followed by other persons close to the child. In particular, parents mentioned relationships with grandparents or siblings and – in second place – the child's regular professional caregivers from school or day care (including the babysitter).

Parents attributed their child's preference for certain people to several factors:

1) **Frequency** of the contact: *"My son has a preference for persons close to him. Whoever he sees less, he needs more time to adjust to."*
2) The feeling of **familiarity** and recognition: *"My sister, who lives in America, was in the Netherlands for a while. My daughter was very fond of her. However, my sister looks a lot like me, has the same voice and way of being. It is in fact more about recognition."*
3) The way persons **interact**: *"If people did exactly the same as us, it would not matter for her who takes care of her."* Some parents also mentioned that their child strongly disliked certain persons. Though they were not really sure about the reasons behind the dislike, they felt that the way the person approached the child and interacted with the child could be an explaining factor.
4) The extent to which persons **fulfil care tasks** for the child: *"He prefers dad, mom and granddad. Family. The people who are the closest to him, also his teacher. Basically, the people who take care of him the most."* However, one mother nuanced this factor by drawing attention not only to the amount of care which is provided to the child, but by also looking into the nature of the care tasks. She, for example, stated that her child did not prefer her, though she did show preference to certain persons. According to the mother this was because of the (negative) nature of the care tasks she was required to do (e.g., washing her child's face, which her daughter experienced as unpleasant).

Besides these general factors which are given by parents to explain preference, some parents also mentioned that their child's preference seems situation-dependent. In their opinion their child has certain preferences, but only among those people who happen to be present. Moreover, children are sensitive to their parents' emotional state: *"Yesterday, she cried almost the whole time and I was fed up with it. She feels this emotion. So, when her grandfather came by, she preferred him over me"*. In addition, the child's preference sometimes seems need-dependent. Parents frequently reported that their child knows who they prefer to get cuddles, to get food, to play or for comfort.

In contrast, some parents doubted that their child has a clear preference for certain people. These parents, though limited in number, indicated that their child is able to discriminate between familiar or unfamiliar persons. However, in their perspective, this is not necessarily associated with a preference for someone. One mother shared this feeling: *"I am not sure about preference, but she clearly recognises certain people, like grandmother and grandfather. Can we call this preference? I am not sure, but it is recognition though."* More strongly, a few parents were certain that their child did not develop a preference for certain persons: *"As long as you follow his pattern of drinking, eating and sleeping, I feel that he does not care"* or *"He feels good with all people who make him feel safe, but he cannot remember how many times he has been comforted by someone"*. One parent explained the lack of preference by the severity of the cognitive delay: *"I think this is mainly because of his intellectual disability… He cannot make associations… and also because of his autism. He cannot make associations such as 'this is my mother' or 'that is my father' due to his limited cognitive level"*.

3.1.2. My child has a hierarchy in preferred persons

The majority of parents, who reported about their child's preference for more than one person, were moreover able to discern a hierarchy in all the preferred persons mentioned. Mothers seem to have a special place on top of this hierarchy in a large number of families. One mother presented this as an "if-then" reality: *"He is really mother-oriented, but if I am not there, then there is his father. I am all the way on top"*. The reason behind this absolute preference for mother is often sought in the amount of time spent with the child (e.g., *"Indeed, I also take a bath with him and I lay with him in his bed"*). Almost equally in number, the child's parents together were placed at the top of the hierarchy. Other persons, for instance grandmother and grandfather, were only incidentally mentioned as most preferred persons (especially when they gave the child lots of individual attention by doing fun things together). Again, the child's hierarchy in preferred persons could be situation-dependent according to some parents. One parent explained: *"Normally there is no difference between us as parents, but sometimes she does differentiate. When one of us is more stressed, she feels this and prefers the other one"*.

A smaller number of parents did not recognise a hierarchy in preferences of their child. In their view, their child's preference is associated with the distinction between familiar and unfamiliar persons, but there is no further rank order within.

My child expresses preference for certain persons

The majority of the parents clearly recognised signals shown by their child which express his/her preference for someone. Though there were a lot of individual differences between children regarding their expression of preference signals according to parents, three broad categories can be discerned. First, the parents perceived that their child shows more positive affect towards his/her preferred person(s). More particularly, they noticed their child giving expression to positive emotions by smiling more, being enthusiastic, clapping their hands and vocalising more. Second, they noticed more (physical) contact seeking and calling for attention, including looking at the preferred person(s) and going towards the person(s) to cuddle him/her. As one parent phrased it: *"See how he lifts his arms up. Cuddling, crawling towards us and lifting his arms up meaning 'I want to be with you'"*. The third broad category, according to parents, involves the characteristics of their child's reactions. Parents reported their child to react more quickly, to be more intense or more frequent in interaction with his/her preferred person(s). One mother saw more intense emotions in her son among his preferred persons: *"He is more happy and also more sad when he is among people who make him feel good"*. Some parents felt, however, that their child's preference signals are the most perceptible on certain defining moments, such as when the child feels ill or needs to go to sleep (*"You see the biggest difference in her behaviour when she goes to sleep. She needs the secure and familiar feeling of people she knows to feel safe and to sleep well"*).

3.1.3. My child uses me as a stress regulator

Almost all parents reported on their vital role as external emotion or stress regulator for their child in times of distress. Especially physical contact and proximity was identified as crucial, going from being near the child, soothing the child, caressing the child, cuddling or heavily embracing the child. One mother acknowledged this as follows: *"Often, he becomes calmer when he sees that I am nearby. If that is still not enough, I put him right next to me and then I feel that he becomes physically less agitated."* Sometimes parents need to take it a step further: *"If you caress him, that can be insufficient. He needs to be cuddled"*. Emotion regulation in this tactile, physical way, is often accompanied by diverting attention *("creating a new situation for the child"*). For some parents, this is only a second-order remedy, for other parents, it is of equal value as physical contact. The way parents change the situation also varies across families, ranging from bringing the child to a calm and quiet room, giving him/her familiar objects (e.g., pacifier), taking the negative stimuli away from the child to distracting the child with positive stimuli (e.g., singing a song). According to their parents, a few children only accept this second way of stress regulation and become even more upset from physical contact with their parent: *"When he is really frustrated or stressed, you cannot come too close. He will bite, pull your hair or take your glasses"*.

In addition, some parents indicated that whether comfort is more or less successful is dependent upon the way the parent is feeling at that time (e.g., parents who are fed up with the crying, are less efficient in providing comfort), personal characteristics (e.g., "*It is because I have the patience to comfort him.*") or the reason why comfort is needed (e.g., in case of serious pain or sickness of the child providing comfort is extremely difficult).

Besides parents being one of the most important stress regulators for their child, some children are in addition able to comfort themselves to a certain extent according to the parents. They manage to regulate their emotions by taking their favourite toy, by shielding themselves from noise or by actively seeking proximity or attention from the parent, for example. However, in case of more intense emotions, parents often take over: *"When it is a small thing, he will soon find something that is of interest to him and then he is fine. However, when he experiences intense emotions, you need to help him"*.

3.1.4. My child prefers my comfort in times of distress, but a stranger could also provide comfort

Almost all parents reported that their child has a clear preference to be comforted by mother and/or father in times of distress. In second place, other persons close to the child, such as grandparents or professional caregivers, would also be able to provide comfort most of the time, though less efficiently. However, with regard to the question whether a stranger would be able to provide comfort as well, parents' answers were more diverse[4] . A first (small) group felt that a stranger would probably not be able to comfort their child. One mother said: *"If a stranger tried to comfort my child, he would start to search for people he does know"* or *"It has happened more than once that the care organisation calls us because they cannot quiet her. I drive over then and in the car she is already laughing"*. A second, more common, group of parents nuanced their answer. They felt certain that they are most able to efficiently and quickly comfort their

[4] It is interesting to note that some parents were not able to recall situations where a stranger needed to comfort their child.

child and that their child would definitely prefer to go to them rather than to a stranger. However, they did not rule out the possibility of a stranger comforting their child, though it would take them more time. A third group of parents indicated that their child does not have a clear preference for certain persons with regard to comforting. They felt that their child could easily be comforted by anyone, especially when the optimal comforting strategy for their child is used. One parent reported: *"He will come to whoever is the closest. The closest 'utility object'"*. Other parents noticed that the way of comforting is crucial in order to be effective: *"You need to know how to comfort her, which words you cannot say. For example, you cannot say 'it's over' or 'we are going to sleep', because she will get more distressed. Not everyone knows that"*. Some parents even stated more strongly that if a stranger did exactly the same as them, they would be equally successful.

3.2. As parent, I am/ am not a secure base for my child

3.2.1. Children differ in using us as parents as a secure base from which to explore unfamiliar places

While most parents reported (subtle) exploratory behaviour and (stress) reaction to an unfamiliar environment, they reported clear individual differences in the extent to which children use the parent as a secure base from which to explore. Approximately half of the group stated that their child does not (deliberately) seek any proximity or contact while exploring a new environment[5] : *"He does not check in with us, unless by chance. He would really run away, he would keep on walking. He would walk into the sea until he drowns"*. Some of these parents explained the lack of contact seeking by the excitement of being in a new environment: *"He would be especially interested in the environment, like 'oh, where am I now?'. I don't think that it makes a difference whether we are present or not"*. Some parents do not clearly recognise how they can support their child. The other half of the parents did recognise secure base behaviour in their child, though this could vary across children with regard to the frequency or intensity of the behaviour (for example, parents described both a mere glance at the parent and sitting on the parent's lap to cuddle). Some parents said that their child needs physical contact to overcome the stress evolving from a new environment: *"For example in the waiting room, she will always take my hand. Just to know that she's not sitting alone, that means a whole lot for her"*.

Some parents also reported the importance of "auditory proximity". Due to visual problems of their child, for example, parents noticed their child making noises to check whether they still get response from their parent or felt that their child waits for auditory cues from their parent. One parent recognised the use of auditory signals: "*When I say 'come to mama', she knows that I am still there and even if she is far away, she can find the strength to bridge the distance. Then she knows 'I am not alone here, and I can go by myself for a while'*". For some children, parents described the importance of "visual proximity", stating that their child glances at them or makes eye contact to keep track of the parent. Besides "auditory or visual proximity", some children need some adaptation time close to their parent(s) in order to explore the environment later on. One parent explained this as a process: *"It is a kind of process. In unfamiliar places, we each stay* 20 min *with our son in the beginning. This gives him the time to observe the environment. Then he familiarises himself with the environment, so that is no longer an issue"*.

3.2.2. Children differ in using us as parents as a secure base from which to connect with unfamiliar persons

Not all parents talked about their child's interactions with unfamiliar persons. However, almost half of the children whose parents talked about this issue, need the physical, auditory or visual proximity or presence of their parent in order to establish contact with strangers. Parents described it as needing approval of them to feel secure enough to interact, especially in the beginning: *"He makes sure that we don't go too far. When we are just chatting in the sofa, he will not panic or he will come sit with us. You have to stay close, however, especially the first minutes"*. Some parents fulfil an active role in making connection to other persons (e.g., introducing their child to others). Other parents felt that their child does not need their proximity to talk to or to interact with strangers: *"He will certainly not be sticking to your leg. No, no. He will go straight ahead. The attack is the best defence"* or *"If he can get cuddles from someone, he is happy"*. However, the child's reaction possibly differs dependent on the approach of the person (e.g., the authenticity) or the environment in which they meet the unfamiliar persons according to some parents: *"At home, he will not be more careful or he will not seek more contact with us. If we meet new friends in an unfamiliar place, yes, then he would"*.

3.3. I have a strong bond with my child but there are some (challenging) preconditions to be met[6]

3.3.1. I have built a good bond with my child, but it is one of a different kind

All parents have built a good, strong relationship with their child according to their opinion. The largest group of parents indicated this with certainty. A few parents felt that the relationship only began to form later on. For example, one mother said: *"In the first few months we didn't have a good bond, because she did not like to be held"*. They referred to the challenging first months, in which they had to get to know their child and to adjust to the situation. A small number of parents doubted the quality of the relationship with their child, but eventually described it as positive: *"It is special. I have said before that I am not sure whether I have a*

[5] To take into account the large amount of children with motor impairments and limited mobility, the child's proximity and contact seeking was broadly defined in the current research and exceeded mere physical contact seeking. It was clarified to parents that contact seeking could also include vocalisations, smiling, looking at them, changing their view direction, etc. in order to provide all children with equal chances to show these contact-seeking behaviours.

[6] This paragraph is mainly (not exclusively) focused on the interviews conducted in the study of Vandesande et al. (2019), since the attachment bond and conditions for secure attachment were the explicit focus of that study.

good bond with him, but when he comes to give a cuddle, then I believe I do. I notice that he knows us well and, this way, I believe we do have a strong bond". In addition, a few parents expressed uncertainty about (changes in) the future and how this might affect their relationship, more specifically about their child possibly going to residential care or the child becoming older.

The majority of parents, in particular those who also have other children, described the attachment bond with their child with a disability as one of a different kind. They indicated it as a more physical relationship: *"You cannot really talk or play with him, you have to pick him up. So, the physical component is really important"*. Some parents described it as a less reciprocal bond, with limited feedback from the child: *"It is totally different than with the other children. He needs us. We have to advocate for him, because he does not have a voice. It is not totally one-way communication, but it is, however, to a large extent"*. Another mother could never compare it to a typical mother-child relationship: *"…because it is more precious. We are pregnant with our second child, but he will always be number one. You know he will not live long, it's reality"*.

3.3.2. Learning how to communicate with my child is important to build a relationship

A first precondition to build a good bond, frequently mentioned by parents, is the ability to read the subtle, idiosyncratic signals of their child. This enables them to understand what their child wants or how (s)he behaves, and is a prerequisite to react sensitively. One parent endorsed this idea: *"For the outer world, it is less clear what he wants to say. It is a matter of getting to know him. We know how to interpret his signals and he knows how to react to us. That's where it all starts"*. However, parents described this as a challenging and ongoing learning process of trial and error (*"I want to help him, but I don't know what is going on, so this hinders the development of a good bond sometimes"*). Some parents emphasised that, though communication is extremely important, it remains difficult, especially when certain disability-related characteristics of their child hinder the communication (e.g., co-morbid autism). Some parents acknowledged the useful help of professionals in this process.

In line with the previous idea of the attachment bond being more physical, parents emphasised the importance of non-verbal communication. Parents communicate more frequently through physical contact (*"You can only cuddle him. I also talk to him, but that does not reach him"*) and also noticed that their child's communication was primarily non-verbal (e.g., facial movements). A large number of parents indicated some kind of contact or basal (short) interaction with their child (e.g., through making noises or vocalising). A few parents even recognised this as essential for their bond: "*I am really grateful that she, despite her autism, still searches a lot… how to say this… searches contact. Giving kisses, cuddling and laughing. I enjoy it immensely*".

3.3.3. I need to accept my child and his/her disability to build a relationship

A second precondition according to parents is to digest feelings of sadness and to accept the child and his/her disabilities. In their view, if you cannot be open to your child and to his/her achievements, it is not possible to build a warm and good relationship: *"It is a precondition to see the little things. You have to be happy with every milestone your child reaches to build a good bond"*. It can, however, be difficult for parents to remain optimistic and notice the positive elements at all times. One mother, for example, mentioned the behavioural problems of her daughter as a hindering factor. Also finding the balance between each family member and always adjusting and making choices against the backdrop of the disability proved to be challenging in parents' perspectives. Overall, raising a child with severe disabilities was described by parents as a challenging, but positive experience: *"You will go through rough periods, but it is also an enrichment. You learn to put things in perspective. Your world becomes completely different"*.

3.3.4. Being patiently engaged with my child is necessary to build a relationship

A last precondition which parents found important, is being patient and taking enough time to engage with their child. Parents reported that they need to make time, although not always self-evident, to patiently listen, to observe their child and to physically engage with the child by cuddling, kissing and holding him/her. They also underlined the importance of repetition in order for their child to learn something. The most fundamental element, according to some parents, is simply being there: *"You need to cuddle them, be with them, tell stories… that is what playing looks like for them. It is not the same as building a tower with blocks, it is 'I am with you'"*.

4. Discussion

The purpose of the current study was to gain understanding of parents' perspectives on parent-child attachment among children with severe or profound intellectual disability (ID). Overall, parents ascribed themselves important roles as attachment figures in the life of their child. However, especially with regard to the parent functioning as a secure base, strong individual differences occurred. The current findings illustrate parents' views that developing secure attachment relationships with severely disabled children is challenging but possible.

The study's first aim was to explore what parents felt about their role as attachment figures. On the one hand, parents clearly recognised their role as a safe haven. They noticed their child clearly preferred them and recognised preference signals. Parents, especially mothers, were most often mentioned at the top of their child's preference hierarchy. However, according to parents, their child did develop attachment relationships with multiple caregivers, which is also to be expected from general population research (Ainsworth, 1967; Bowlby, 1969/1982; Howes & Spieker, 2016). In addition, parents functioned, in their view, as a stress regulator for their child and comforted their child most efficiently. On the other hand, parents' opinions on their role as a secure base from which to explore were more diverse. Whereas some parents recognised secure base behaviour in their child when exploring new environments or meeting new persons, other parents did not. This result corroborates some of the findings of Vandesande et al. (2019), from which part of the data for the present study were derived, concerning parent-reported secure attachment behaviour using the Secure Base Safe Haven Observation List (De Schipper, Schuengel, Stolk, & Janssen, 2004). Indeed, items describing safe

haven behaviour (e.g., *"When my child is frightened or sad, (s)he is easily comforted by me"*) were in general found to be more characteristic for children with severe or profound ID compared to items on secure base behaviour (e.g., *"When my child finds something new to play, (s)he draws my attention to it or shows it from a distance"*). Various hypothetical explanations for this finding can be found in literature. First, in order for a child to display secure base behaviour, a child needs to possess certain minimal abilities (such as the ability to crawl towards the mother; Tessier, Tarabulsy, Larin, Laganière, & Gagnon, 2002). However, as Tessier et al. (2002) stated, due to the child's disabilities (e.g., limited locomotion) certain attachment behaviours will be replaced by an alternative expression. These idiosyncratic signals are often subtler and harder to notice (Schuengel & Janssen, 2006) and increase the chances of missing or only subliminally perceiving these behaviours. This first hypothesis corresponds with the high percentage of participants (74.1%) who were classified as having a severe motor impairment and limited mobility in the current sample. Second, parents of children with severe disabilities tend to support autonomy to a lesser extent and show higher levels of intrusiveness in their parenting behaviour (Cox & Lambrenos, 1992; Laing et al., 2010; Potharst et al., 2012). This could limit the opportunities the child receives to explore an unknown environment. Hence, drawing parents' attention to subtle instances of secure base behaviour or enhancing the child's exploratory behaviour could be an important point of action for clinical practice.

The second aim of the study was to examine how parents perceived the attachment bond with their child and to identify preconditions they reckoned important to build a secure relationship. In general, the interviews indicated that parents believed they had built a secure relationship with their child, although this was not self-evident[7] . Moreover, the attachment bond is of a different and more physical nature, compared to the bond of the parents with their other children. A constant throughout parents' answers was time. Both in the process of developing an attachment bond (e.g., extensive period of processing the diagnosis of the child, taking time to get to know their child), and later on, when the relationship has already been established (e.g., self-care, balance with other family members, patiently engaging with the child), parents underlined the importance of taking and making enough time. Given the high prevalence rates of insecure attachment relationships in children with severe or profound ID (Atkinson et al., 1999; Schuengel & Janssen, 2006), clinical practice could benefit a lot from a qualitative insight to support parents in these challenges they encounter. For instance, the issue of parents' time management and work-life balance might be a key theme which deserves further exploration in order to provide targeted support in this regard.

Although the current study is one of the first to explore parents' perceptions of their role as attachment figures for persons with severe or profound ID in a qualitative way, a limitation of the present study is the fact that parents' interviews were not exactly the same for all participants, since they originated from two different research projects. Given the theoretical background and the research aims of each project, the research agendas of the principal researchers may have influenced the interviews (*researchers bias*; Lincoln & Guba, 1985). This difference in research agendas resulted in certain topics not being discussed in one of the projects. For instance, fewer text excerpts dealt with exploration and the preconditions for secure attachment development, since one study questioned this explicitly, while the other did not. However, since both research projects are strongly complementary, it is both justifiable and relevant to analyse the interviews together for three reasons. First, the target group, which is a group that is extremely difficult to recruit in research, is similar in both projects. Second, the same topics were discussed in both samples, since the interview of Vandesande et al. (2019) was strongly inspired by the SEO-R and the SEO-R was administered in the OJKO project. Third, the text excerpts which were analysed for the current study mainly originated from parents' answers on questions that came from the SEO-R interview.

The current article should be viewed as reporting on exploratory research. This study has given ample evidence to show that the theme of attachment is of particular importance to parents of children with severe or profound ID. It was, however, beyond the scope of the article to provide general statements and theories on parents' perspectives and to express parents' opinions in exact percentages. Though we are aware that the lack of exact numbers enforced us to use vague and abstract terms (e.g., 'the majority'), the current article does not want to evoke the illusion of precision and did not aim to quantify statements. Reality is that parents' answers could not always be easily located in one category or another, due to their high context- and moment-dependency and their level of nuance. In addition, it was beyond our scope to classify children based on attachment security. In response to the present study's limitations, future research aiming at theory development, could consider additional ways to guarantee the rigour of the findings (Creswell, 2007; Lincoln & Guba, 1985). For example, providing member checks, which was not provided in the current research due to a significant delay between data collection and data analysis, would be of particular value to heighten the study's credibility and to diminish possible researchers' bias (Creswell, 2007; Lincoln & Guba, 1985; Savin-Baden & Howell Major, 2013). In addition, it was beyond the scope of the current study to identify which components of the parents' perspectives were specific to the target group of children with severe disabilities compared to their typically developing siblings. However, parents sometimes spontaneously drew our attention to the difference. Future research exploring the specificity of parents' answers is, thus, recommendable. In addition, linking observation research on attachment behaviour in children with severe or profound ID (e.g., Vandesande et al., 2019) to parent interviews would be particularly interesting to determine whether or not parents recognise independently observed behaviour, and whether or not parent-reported individual differences correspond with observed individual differences.

To summarise, parents of children with severe or profound ID acknowledged the roles they fulfil as attachment figure, but pointed at several challenges which influence the process of developing secure attachment. These research findings nurture the belief that exploring parents' perspectives provides clinical practice with useful recommendations concerning interventions to overcome challenges that parents encounter in developing a secure emotional tie with their child. From a "developmental systems perspective" (Guralnick, 2011) as well as an attachment perspective (Bowlby, 1969), anticipating on these challenges and strengthening parents in

[7] Note, however, that it is impossible to draw conclusion on the quality of attachment based on parents' interviews.

supporting their child to explore would benefit the quality of the parent-child relationship. Indirectly, focused intervention which is driven by a parental perspective could potentially contribute to attachment security, which can both enhance parental self-efficacy and the child's social-emotional development, the child's mental health and the child's cognitive and motor development by increasing chances for exploration.

Declaration of Competing Interest

None.

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