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The lived experience of participation of 5- to 8-year-old children with developmental problems: an inductive thematic analysis

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Abstract

Nederlands

Introductie: Sinds de publicatie van het ICF-model steeg de internationale interesse voor participatie als doelstelling binnen de gezondheidszorg. Wetenschappelijk onderzoek en de klinische praktijk zou echter baat hebben bij een duidelijke en uniforme omschrijving van het concept participatie.

Doel: Deze studie beoogde de subjectieve ervaring van participatie bij jonge kinderen met ADHD, ASS of DCD in kaart te brengen en hiermee bij te dragen aan een volledig en geldig inzicht in de participatie van kinderen.

Methode: Deze fenomenologische studie voerde drie opeenvolgende interviews en één camera-opdracht uit bij 16 kinderen van vijf tot acht jaar en hun ouders. De data werd geanalyseerd aan de hand van een inductieve thematische analyse.

Resultaten: De doorleefde ervaring van kinderen omtrent hun eigen participatie bestaat uit thema's gerelateerd aan het kind, gerelateerd aan de activiteit, verbindende thema's en mediatoren. Succesvolle participatie vloeit voort uit een goede afstemming van kindgerelateerde en activiteitgerlateerde thema's. Vaak waren er mediatoren die de succesvolle participatie faciliteren of belemmeren.

Conclusie: Er werd een thematische kaart van de doorleefde ervaring van de participatie van jonge kinderen voorgesteld. De thema's en de thematische kaart sluiten goed aan op ander onderzoek over de participatie van kinderen en op een breder theoretisch kader van menselijk handelen. Door deze thematische kaart samen te voegen met een eerdere kaart van de participatie van kinderen, dragen de inzichten uit deze studie bij tot een geldiger begrip van het concept participatie.

Aantal woorden masterproef: 10206 (exclusief inhoudstafel, bijlagen en bibliografie)

Abstract
English

Introduction: Since the publication of the ICF model, international interest in participation as a health outcome has intensified. Nevertheless, research and clinical practice would benefit from a clear and uniform description of the concept of participation.

Aim: This study aimed to capture the subjective experience of participation of young children with ADHD, ASD or DCD to contribute to a full and valid understanding of children's participation.

Method: This phenomenological study performed three consecutive interviews and one camera assignment with 16 children from five to eight years old and their parents. The data was analysed via an inductive thematic analysis.

Results: The lived experience of children on their own participation consists of themes that were child related, activity related, linking themes or mediators. Successful participation results form a good match between child related and activity related themes. Often there were mediators facilitating or hindering successful participation.

Conclusion: A thematic map of the lived experience of the participation of young children is proposed. The themes and thematic map fit well with other research on the participation of children and within a wider theoretical framework on human occupation. By merging this thematic map with an earlier map of children's participation, the insights of this study add to a more valid understanding of the concept participation.

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Preface

"(..) children can be active research participants who will help expand the knowledge base of occupational therapy." (Curtin, 2001)

Voor u ligt het verslag van een boeiende reis doorheen de leefwereld van jonge kinderen. Verscholen achter dit product zit een enorme verzameling van leerervaringen waar ik oprecht dankbaar voor ben. In de korte tijd van iets meer dan een jaar ben ik verschillende inhoudelijke en methodologische inzichten rijker geworden. En niet alleen dat. Gezien de aard van het onderzoek, kreeg ik de kans om diepgaande gesprekken te voeren met verschillende mensen van sterk wisselende achtergronden, leeftijden, interesses en dromen, wat me als persoon veel rijker heeft gemaakt.

Ik dank daarom oprecht dra. Marieke Coussens en dr. Dominique Van de Velde voor de uitgebreide ondersteuning, de vele leerervaringen en de kans om bij te dragen aan de onderbouw van het beroep dat me nauw bij het hart ligt.

En in het bijzonder bedank ik Batman, Ben, Bent, Beyblade, Filouke, Lientje, Loeizui, Miekie, Minnie, Mortis, Nardas, Noem, Rudy, Super Zorro, Thomas, T-Rex en jullie ouders om in te tekenen op een soms heel spannende ervaring en me te verwelkomen, niet alleen in jullie huis, maar vooral in jullie leefwereld.

1 Introduction

1.1 Background

Since the publication of the International Classification of Functioning (ICF) by the World Health Organisation (WHO, 2001, 2007) contemporary healthcare has experienced a paradigm shift from a purely biomedical towards a bio-psycho-social (BPS) conception of disability and illness (Van de Velde, Eijkelkamp, Peersman, & De Vriendt, 2016). By using the ICF as a BPS framework, the focus of healthcare moves away from disfunction and disability towards client-centred goals concerning meaningful activities and participation. As a result, international interest in 'participation' as the ultimate health outcome has intensified (Imms et al., 2016; Van de Velde et al., 2017).

The ICF defines participation as "involvement in a life situation" and participation restriction as "problems an individual may experience in involvement in life situations" (WHO, 2001, 2007). This remains a vague definition which leaves it to researchers and clinicians to provide their own description when studying or measuring participation. However, the construct of 'participation' is rarely defined sufficiently in research and practice (Dedding, 2009; Dijkers, 2010; Imms et al., 2016; Van de Velde et al., 2017).

That's why the systematic review of Imms et al. (2016) aimed to delineate the concept of participation as it is currently used in research with children with disabilities. In the language of the reviewed articles they identified two themes as describing the participation concept: involvement (including subthemes of affect, motivation and social connection), and attendance (including frequency and range of activities).

Three other themes were identified as describing related concepts:

1. Preference (as a predictor of participation): including subthemes of meaningfulness and choosing
2. Activity competence: including the subthemes of competence and appropriate actions
3. Sense of self: including personal growth and self-perception elements such as self-competence or confidence.

This circular interactional interplay takes place within an environment whose properties availability, accessibility, affordability, adaptability and acceptability have an influence on participation.
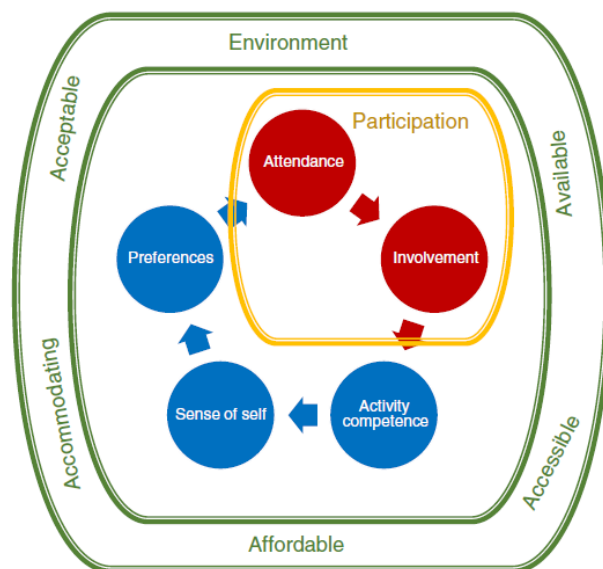
Figure 1: Participation and participation related constructs (Imms et al., 2016)

1.2 Relevance

Occupational therapists believe that health is influenced by the ability to choose and participate in meaningful occupation (Townsend & Canadian Association of Occupational, 2012). But because of the lack of a uniform and universal definition there *"(…) are challenges to measuring participation in everyday life, including operationally defining participation, distinguishing participation from activity (within the ICF framework), addressing objective (e.g. number of situations, frequency, location) versus subjective (e.g. enjoyment, satisfaction, importance) dimensions of participation, incorporating environmental contexts, and evaluating participation over time."* (Field, Miller, Jarus, Ryan, & Roxborough, 2015)

Knowing that children with disabilities are at increased risk for limited participation in everyday occupations, (Heah, Case, McGuire, & Law, 2007) having a clear and uniform definition of participation is needed to develop related interventions and assessment tools (Imms et al., 2016).

1.3 Research problem

The conceptualisation of participation according to Imms et al. (2016) was solely based on language used by authors researching the participation of children with disabilities, not including the perception of the children themselves. The subjective experience of participation has been studied in adult populations (Haak, Ivanoff, Fänge, Sixsmith, & Iwarsson, 2007; Häggström & Lund, 2008; Hammel et al., 2008; Van De Ven, Post, De Witte, & Van Den Heuvel, 2008), but to our knowledge not yet with children.

In creating a guideline for research with children with disabilities Whyte (2005) found that *"The voices of children with disabilities have been largely absent from research on children with disabilities. (...)"*. While *"It is seen as essential that disability research accurately reflects the perspectives of people with disabilities and remains focused on the issues of greatest importance to them."*

When asking questions related to the child's perspective however, researchers have traditionally used adults as proxies (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). This while, based on extensive research, Dedding (2013) shows that parents are not reliable interpreters of the child's perspective.

There has been extensive research on the participation of children with physical (Bult, Verschuren, Lindeman, Jongmans, & Ketelaar, 2014; Chiarello et al., 2016; Shields & Synnot, 2016) and intellectual disabilities (King, Shields, Imms, Black, & Ardern, 2013; Shields, King, Corbett, & Imms, 2014). Far less research has been done on the participation of children with more "invisible" disabilities (Adair, Ullenhag, Keen, Granlund, & Imms, 2015). This while recent studies

claim 6% of the world population, regardless of age, has Developmental Coordination Disorder (DCD)[1] (Farmer, Echenne, Drouin, & Bentourkia, 2017), 1,5% has Autism Spectrum Disorder (ASD)[2] (Lyall et al., 2017) and 5% has Attention Deficit Hyperactivity Disorder (ADHD)[3] (Sayal, Prasad, Daley, Ford, & Coghill, 2017).

1.4 Research objective

This study therefore aimed to capture the subjective experience of participation of young children with ADHD, ASD or DCD and thereby contributing to a full and valid understanding of children's participation. Generated insights can then contribute to the use of a valid construct in research and clinical practice focussing on participation of this population.

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[1] Substantial difficulties in the acquisition and execution of coordinated motor skills. (APA, 2013)
[2] Persistent deficits in social communication, social interaction and restricted, repetitive patterns of behaviour. (APA, 2013)
[3] A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development. (APA, 2013)

2 Method

2.1 Design: an inductive thematic analysis

This study aimed to develop a comprehensive understanding of the meaning of participation from the perspective of those experiencing it by doing in-depth interviews with a sample of children aged 5 to 8 years old. Thus it fits within the descriptive phenomenological tradition (Vaismoradi, Turunen, & Bondas, 2013). After data collection, analysis will focus on identifying, analysing and reporting patterns (or "themes") within data collected from the children. This method of qualitative data analysis is referred to as "thematic analysis" (Braun & Clarke, 2006). Since there are no previous studies dealing with the lived experience of participation of young children, an inductive approach was used, meaning the coded categories were derived directly from the collected data.

The study protocol also incorporates some elements of participatory research (Broström, 2012; Dedding, 2013; Hart, 1992) as children had a voice in the decisions concerning informed assent, interview protocol and dissemination of findings. This will be more widely discussed further in this dissertation under "Participatory research".

The research protocol was designed and reported on in accordance with the *"Guidelines for critical review form: Qualitative studies (Version 2.0)"* (Letts et al., 2007), also taking into account the guideline on *"Research with children with disabilities"* developed by Whyte in 2005. Given that the guideline of Whyte is accompanied by a specific checklist for use in research with these children, it was selected above other available guidelines.

The researchers were trained according to Whyte's guidelines regarding the planning, implementing, analysing and disseminating of the research.

2.2 Ethics committee

Approval of the ethics committee of Ghent University Hospital was requested and obtained in January 2018. The Belgian registration number B670201835100 was allocated to the study. The approval was valid from January 2018 to September 2019.

2.3 Sampling strategy

Given that participation problems can manifest themselves in early childhood (Khetani, Graham, & Alvord, 2013), this research focused on the young child. To ensure that pre-operational and concrete-operational thinking is sufficiently developed to make reasoning possible (Feldman, 2016), a calendar age of five years was used as the lower limit. For the same reason, only children with normal intelligence were included. Given that participation between different ages can differ significantly in diversity and intensity (Law et al., 2006) and to ensure the representativeness of the sample, the upper limit for inclusion in the study was determined at the age of eight years and eleven months.

Different studies have been done on the participation of children with motor and intellectual difficulties (see introduction). To our knowledge less to none have been done on the more invisible developmental problems like ASD, DCD and ADHD. This study focuses on the latter.

To ensure there was no language barrier that could hinder the collection and analysis of data, children speaking Dutch or English were included in the sample. Both languages are spoken fluently by the researchers.

The inclusion criteria for the purposive sample therefore were:
- Ages five to eight
- Normal intelligence: a total IQ between 85 and 115
- Speaks Dutch or English at home
- ASD, DCD, ADHD or comorbidity

In defining these criteria, the study aimed to put together a heterogenous sample which makes it possible to transfer the findings to children with the same criteria.

2.4 Recruitment

A list of seventy participant sources was compiled, based on the data on desocialekaart.be, which is a database that contains the contact information of all care facilities and care providers in Flanders and Brussels.
The list contains:

- *"Multifunctionele centra"* (MFC), Multifunctional centres, which provide both outpatient and residential paediatric rehabilitation
- *"Centra voor ambulante revalidatie"* (CAR), Centres for outpatient rehabilitation, which provide outpatient paediatric rehabilitation
- Centres of expertise, which provide information, capacity building and advocacy for selected patient populations
- *"Thuisbegeleidingsdiensten"* (TB), Services that provide support at home
- *"Centra voor geestelijke gezondheidszorg"* (CGGZ), Centres for mental health care, which provide outpatient paediatric mental health care

To increase the chances of recruiting participants that meet the inclusion criteria and that have information on children's diagnoses and intellectual capabilities, following participant sources were excluded:

- Centres for people with intellectual or motor disability
- Centres providing services for young people and adults only
- Schools for special needs education
- Day-care centres
- Care farms
- (Special needs) leisure organizations

Aside from these indirect ways of recruiting, also twelve Facebook self-advocacy groups were addressed for direct recruitment.

To recruit potential participants from these participant sources, a recruitment poster was made (see appendix 2). It contains a brief explanation of the study, the inclusion criteria, all practical information, information on the researchers involved in the study and contact information for further elucidation and enrolment. People interested in participating in the study could register their contact details in an online form or via phone call or mail to the researchers. Those details were: (1) Name of the parent, (2) Name of the child, (3) Birth date of the child, (4) Address, (5) Phone number and (6) Email address.

The online form was available until data saturation was reached. Then it was replaced with a message asking people to leave their contact details if they were interested in participating in further research.

Potential participants were then contacted via telephone for further information (see information form in appendix 3). They were given some brief additional information about the research project and were informed that a detailed explanation would be provided during the first visit and that the informed consent (see further) for parent and child would be mailed in advance. Researchers checked if there were any pressing questions about the research project and asked the parents to read the informed consent together with the child carefully as this would be used to ask for permission to invite the child to participate. In doing this the child would have the time to think about it before the first visit.

Inclusion criteria - language spoken at home, diagnosis and intelligence – were checked. Some information was collected to facilitate the first interview:

- The child's preferred mode of communication. For example, non-verbal communication, oral or sign language, augmentative and alternative communication (AAC), drawings and so on.
- The child's preferred way of greeting a stranger and their usual attitude towards strangers.
- Their preferred activity to build rapport. If there would be any picture or a drawing present in the vicinity which the child can talk about.
- The possibility of a quiet place familiar to the child to do the interview.
- The ability of the parent to be present during the entire interview.

When inclusion criteria were met, the specifics of the visits were discussed.

- The time and date for the three visits. The second visit one week after the first and the third preferably one week after the second.
- Possible food restrictions to be aware of regarding the drinks and snacks that would be offered during the interviews.

After the phone call, written confirmation of the appointments was provided via e-mail. And the informed consent for parent and child was sent via analogue mail and e-mail.

2.5 Informed consent

Given that *"researchers have found that most elementary-school-age children have the capacity to provide assent as defined by federal regulations"* (Weithorn & Scherer, 1994 in Curtin, 2001; Lambert & Glacken, 2011) and given both parent and child were participating in the study, both an informed consent (IC) for the parent and an informed assent (IA) for the child were provided. *"Different to consent in that it is not a legally endorsed process, assent refers to children's affirmation to participate. (…) It is a process where a minor is afforded with the decision about whether they would like to participate in research and this*

decision is complemented by a legally recognized surrogate decision maker."
(Lambert & Glacken, 2011). We followed the advice form Curtin (2001) that
states:

> *"The children need to be given an explanation of the research in words*
> *that they can understand and be told with whom the information will be*
> *shared. Children also need to be told that they have a right to dissent,*
> *that a decision not to participate will be respected, and that they can stop*
> *at any time with no consequences."*

Since *"(…) even simplified written IC forms risk being inaccessible to many*
young people, and may not provide enough reassurance to participate" (Ruiz-
Casares & Thompson, 2014), images were provided for every concept in the
informed assent. All the information in the assent was communicated verbally
and face to face to the child twice. First by the parent and again during the first
visit by the researcher. Each time it was checked with the child if everything was
clear.

The first version of the informed assent was pilot tested with a five year old child
without developmental issues. Based on their feedback some wording was
rephrased and some images were added. Other images where there was doubt
(for example the "stop" image), the children could confirm that they conveyed
the intended message clearly. The informed consent and the final version of the
informed assent can be found in the appendix four and five.

2.6 Data collection

2.6.1 Rationale

Data collection consisted of three interviews where in each subsequent interview the researcher tried to gauge deeper into the thoughts, emotions and perception of the child. (see further)

The data collection was tailored to the individuality of the child. All interviews took place in the home of the child and in the presence of the parent to ensure a known and safe environment. Language and concepts used in conversations were adjusted to the language and intellectual development of the child. The interviewing researcher used open questions to only generate data related to the perception of the children and avoid bias originating from narrow questions. To help with recall and stimulate conversation after the first interview the children were asked to take pictures of the activities and contexts in which they participate. Those pictures were discussed in the second interview. As seen in other qualitative research with young children (Elvstrand & Närvänen, 2016), interviews were limited to 30 minutes.
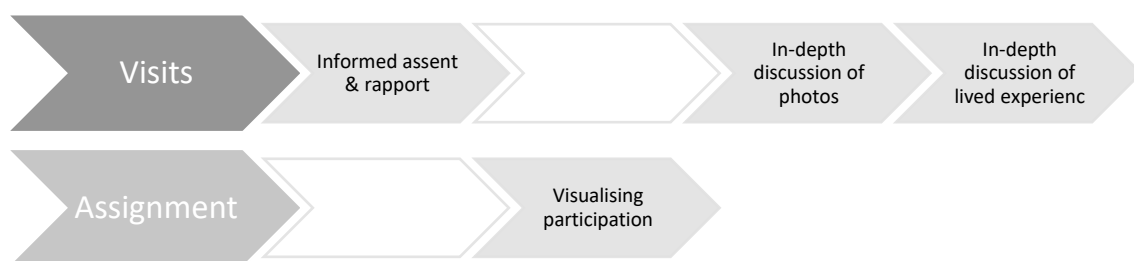

Figure 2: Data collection

Knowing that *"(…) engaging children in qualitative research and eliciting their voices involve different challenges and research methods than research with adults"* (Curtin, 2001), the interview protocol (see appendix) was composed following the guidelines and advice of Whyte (2005) and Curtin (2001).

In doing so, the researchers made sure to (Curtin, 2001):

1. Examine their own beliefs regarding children's competencies: Researchers maintained a non-adult-centric view on children as being "human beings, not human becomings". They recognize children as experts about their own lives.

2. Define a different adult-child relationship that minimizes the power differential: Researchers have refrained from behaviour that could be interpreted as authoritarian, judgemental or interfering. They maintained a responsive versus a dominating stance towards the input of the participating child.

3. Learn the child's communication styles in order to elicit the children's perspectives and develop a common language: The researchers sought to learn the vocabulary and phrase length the child uses and refrained from using complex adult language. They also kept in mind to use non-verbal conversation techniques (like drawing, body language, …) where relevant.

Specific ways in which this was accomplished will be pointed out in the interview protocol below.

All interviews were recorded on video to make a conversion to a transcript possible. To avoid that a lot of the children's attention would go to a big camera on an impressive tripod, the researchers chose to use a smartphone on a small 3D-printed mount that could be placed on any surface in the vicinity. The use of the smartphone and mount combination was also pilot tested in the same convenience sample of typically developing children.

Figure 3: 3D-printed tripod - https://www.thingiverse.com/thing: 2430714
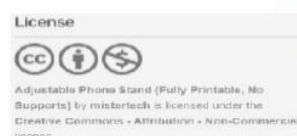
Results from the pilot interviews indicated that it was desirable to put a reminder on the interview protocol to put the smartphone on video mode. And that the thirty-minute duration of the interview was well chosen given that the children began to give signals of fatigue after about half an hour.

2.6.2 First visit: Informed assent and rapport building

At arrival at the home of the child, they and their parent were greeted in their preferred way. Researchers provided a drink while explaining the research project, visits, camera assignment and informed consent and assent using the images discussed earlier. Parents were asked to jump in when other vocabulary or phrasing would be better suited to explain the current topic. At the end of the explanation, the child was asked to pick their own pseudonym. The child was then asked where everyone should sit for the interview and if they would like to help setting up the camera.

During the first interview the researcher joined the child in one of their preferred activities. This was intended to build rapport and to facilitate conversation. When the child gave the impression of being shy or overwhelmed, they were asked to tell something about a picture or drawing they created.
The open interview then started with the first question "What do you like to do?" and built there on. Researchers avoided to steer the conversation in any direction. Instead all follow up questions were focussed on getting more in-depth information on the story of the child, so they could guide the conversation. For example: Tell me more. What do you think about that? How does that make you feel?
In case of slow conversation there were some additional questions e.g.: What did you do today, yesterday, this week? What are things you don't like to do?

In every interview the child was assured that every answer would be a good answer. The researcher knows absolutely nothing and really wants to hear what the child thinks. But even so, it's okay if they don't know or want to give an answer.

If they found it hard to answer, researchers first examined their part in the occurrence. For example, by asking a vague question.

2.6.3 Camera assignment: Visualising your participation

"Participatory photography provides young people with a promising and effective tool to both express how they see the world and engage in dialog about their experiences." (Ruiz-Casares & Thompson, 2014)

To help the children recall their experience of and their perception on their participation they were given a children's camera for a week and were asked to take as many pictures as they wanted of the things they do. Letting the child use the camera by themselves for a week would help to reduce bias, but raised some challenges:

- The camera was very robust. Dropping it would not result in damage.
- To diminish the chance of forgetting and losing the camera and to help them remember to take pictures, there was a waist bag provided to wear the camera on their body.
- Extra batteries were provided for when the originals ran empty.
- Aside from verbal instructions for the use of the camera, parents were also provided with the manual.
- There was an accompanying letter (see appendix) for parents, family members, teachers, coaches etc. asking them to help the child remember to take pictures. They were also free to take pictures of the child during activities.

2.6.4 Second visit: More in-depth questions based on the pictures

Again, the researcher asked the child where everybody should sit and if they wanted to help set up the camera. The assurances of giving good answers, having the right to stop the interview etc. were repeated.

In this interview, the pictures from the camera assignment were discussed. The child and parent were assured that the pictures themselves would not be the data for the research, but only what the child could tell about them.
The researchers provided a snack for during the interview.

When the child had difficulties in finding ways to express their thoughts and emotions, researchers asked the parent to help with some guiding questions or to give an answer from their perspective. That gave the child the opportunity to agree, to disagree and/or to elaborate. This conversation between parent and child often led to a deeper understanding of the thoughts and feelings of the child.

2.6.5 Third visit: An in-depth interview about their lived experience

The same assurances were given for the last interview. The researcher gave a verbal summary of the data analysis of the two previous interviews to do a member check. The child was asked for feedback on the interpretations and, where helpful, was asked to elaborate on some aspects of their story. Again, with or without some input of the parent to trigger further responses of the child.

The series of interviews was wrapped up by asking the child and parent for feedback on the research, their ideas on disseminating the findings and by offering a small thank you gift.

2.7 Data analysis

The protocol for data analysis was established using the six recursive phases described by Braun and Clarke (2006). Analysis was done with the help of NVivo10 from QSR International.

2.7.1 Familiarising with the data

Both researchers transcribed the videos from their interviews. They obtained a "sense of the whole" through actively reading and rereading the transcripts several times while noting down initial ideas, like possible patterns and meanings.
In converting video files to transcripts, advice of Silver and Lewins (2014) was taken into account. For example: anonymising as early on as possible, using identifiers as an efficient source management system, using small line spacing, etc.

2.7.2 Generating initial codes

The researchers produced initial codes that identify "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 2009) for each part of the data. They worked systematically through the entire data set, giving equal attention to each data item, and identify interesting aspects in the data items that may form the basis of repeated patterns across the data set. They ensured that all actual data extracts were coded, and then collated together within each code.

Advice of Braun and Clarke (2006) was taken into account to:

- Code for as many potential themes or patterns as possible.
- Code extracts of data inclusively – i.e., keep a little of the surrounding data if relevant.
- Remember that you can code individual extracts of data in as many different "themes" as they fit into.

2.7.3 Searching for themes

Once all data had been initially coded, the researchers started to analyse the codes and considered how different codes may combine to form an overarching theme, resulting in a collection of candidate themes and sub-themes. The node tree within the program NVivo10 was used to keep overview of the mapping of all themes.
To diminish the risk of bias, researchers discussed independently generated codes and themes during peer debriefing sessions to generate a uniform body of interwoven themes.

Starting from the analysis of the interviews of the thirteenth participant no more new codes or themes were generated. New data was only added as examples of pre-existing codes. This remained the same for participant fourteen, fifteen and sixteen. Researchers then concluded data saturation was reached.

2.7.4 Reviewing themes

In this phase the researchers reviewed and refined the themes by reading all collated extracts for each theme and considering whether they appear to form a coherent pattern. If not, the theme was reworked.

2.7.5 Defining and naming themes

The researchers described the essence of what each theme is about and its relation to other (sub)themes and the whole. Chosen names needed to be concise and immediately give the reader a sense of what the theme is about. To contribute to the conformability of the generated results, vivid transcripts extracts were selected that would best illustrate each theme.
As with many thematic analysis (Vaismoradi et al., 2013), the researchers also created a thematic map of the themes and their relationships.

2.7.6 Producing the report

In this last phase, the researches sought to tell the complicated story of the data that provides a concise, coherent, logical, non-repetitive and interesting account of the data that relates back to the research question and literature. The result of phase five and six are represented under "Results" and "Discussion".

3 Results

A total of 31 people registered to participate in the study of which 22 people were successfully contacted for further information before data saturation was reached. Two children did not meet the inclusion criteria concerning age or intelligence quotient. One parent decided not to participate in the study as they were hoping the study would result in a diagnose for their child. One parent did not see any possibility in their agenda to plan three interviews.

18 people were then sent the informed consent and assent. Two children refused to participate in the study after discussing the informed assent with their parent. One parent had to cancel the third interview and was unable to schedule it again within the time frame of the study.

Table 1: Characteristics of the sample

Information	Number	Percentage
Age		
5	3	19
6	8	50
7	3	19
8	2	12
Gender		
M	12	75
F	4	25
X	0	0
Disorder		
ADHD	2	12
ASD	2	12
DCD	5	32
ADHD+ASD	3	19
ADHD+DCD	0	0
ASD+DCD	3	19
ADHD+ASD+DCD	1	6
Province		
West Flanders	0	0
East Flanders	13	81
Antwerp	3	19
Flemish Brabant	0	0
Limburg	0	0
Brussels C.R.	0	0

This resulted in a successful completion of 47 interviews in a sample of 16 participants before data saturation was reached. The remaining people who registered via the online form were kindly invited to leave their details to be contacted for participation in follow up research.

After analysing the data via an inductive thematic approach in the program NVivo 10, 14 clear themes emerged. When discussing participation, children uttered both thoughts and feelings about themselves and about their activities. In addition to those themes and their subthemes, they also hinted at connections or mediators between those themes.

Thoughts and feelings about themselves could be categorised in (1) Self-awareness and identity; (2) Convictions, wishes, preferences and choices and (3) Experience of and reflections on finished activities.

Thoughts and feelings about activities could be categorised in (1) Features of the activity; (2) Context of the activity; (3) Purpose to which the activity contributes; (4) Interactions with others and (5) Features of activity materials.

Connections between themes were categorised as (1) Thoughts resulting in experience; (2) Actions resulting in emotions and (3) Appreciation of activities based on their activity competence.

Mediators were categorised as (1) Access to activities; (2) Appreciation of others and (3) Appreciation by others.

The themes and subthemes mentioned above will be discussed at length below.

3.1 Thoughts and feelings about themselves

<u>Self-awareness and identity</u>

All children talked about features of themselves. Most of them mentioned some skills they had or even demonstrated them during the interview. Sometimes they would also point out limitations they faced, like being near-sighted or having a neurological disorder.

> *Researcher: Are you ready for the difficult question?*
> *Ben: I am. I am good at difficult questions. And my brain is full of ideas.*

> *Researcher: What is not fun? (...)*
> *Filouke: Falling.*
> *Researcher: Do you fall often?*
> *Filouke: Yes.*
> *Researcher: Can you give an example?*
> *Filouke: I have stitches in my chin. And here too. *Indicates eyebrow.**
> *Researcher: Oops. How did that happen?*

Filouke: I was on number one on my gears. And actually, that is for the mountain. And I had fallen because that was too fast.
Researcher: So you fall when you cycle.

Researcher: And why did you take a picture of your glasses? Because otherwise you do not see well?
Super Zorro: I can see that, but I am farsighted and close-sighted. But I still have to wear that, because it can still go wrong. But I already have better glasses than last year.

Apart from their own functioning, there were also other features that formed their identity. For instance, belonging to a group, like a family or a youth leisure group, or having a diagnose.

Ben: The Akabé [youth work] is something. Is a group. I'm in the Kapoenen [age group within the organisation].

Loeizui: I have ADD so ... (...)
Researcher: What is ADD?
Loeizui: Uh ... That's how my head ... my brain works a little differently. That is ADD. I know that.

Convictions, wishes, preferences and choices

Many children could also indicate what their personal convictions were. For instance, their view on rights of usage or property of an object, the division of tasks, what constitutes good or bad behaviour, the importance of school and certain educations or professions, and so on.

[Parent: You do not want to tidy up. You always say to me "I did not do that. My brothers did that. So, I do not have to tidy that up."]
Rudy: But that is true. Otherwise, that is not fair.
Researcher: Yes. Everyone must tidy up his own things?
Rudy: Yes

Apart from that, they have their own desires. Those can be small and short term like eating more ice cream, having more toys or having more school holidays. But they can also be big and long term like doing volunteer work when they reach secondary school or looking forward to a job when they are an adult. Or somewhere in between, like being better in maths.

> *[Parent: And did you tell Birger what you want to do if you do not play tennis anymore?]*
> *Beyblade: Oh yes! Go to the scouts. I like to get dirty.*
>
> *[Parent: And Rudy wants to become a veterinarian.]*
> *Rudy: yes.*
> *Researcher: Why? What is so nice about being a veterinarian?*
> *Rudy: That I can heal giraffes.*

They also told anecdotes of their own preferences for things like types of toys, foods, flowers, … and the ability to act upon them. Like choosing their own clothes or having a say on where to go on holiday or what to eat for dinner.

> *Researcher: So, you also like to practice language?*
> *Rudy: Yes!*
> *Researcher: And why?*
> *Rudy: Because that seems so nice!*
> *Researcher: And why does that seem so nice? What is nice about language?*
> *Rudy: Working.*
> *[Parent: Rudy likes to work. He does not like playing at school.]*
>
> *Researcher: And what are you going to do in the afternoon?*
> *Thomas: Eat pizza. First, we go eat pizza and then we are going to do something. (...)*
> *Thomas: I said that to my dad. I want to eat pizza.*

<u>Experience of and reflections on finished activities</u>

Sometimes children were reflecting on activities they had done or interactions they've had. They expressed their thoughts and feelings on the activity, the product thereof, conflicts they had or appreciation they had received. These would lead to a certain measure or lack of satisfaction with the activity.

> *[Parent: Sometimes, outside on the square others don't let you play along. And then you come home very sad. Why can't you sometimes play along with the others?]*
> *Ben: Because I have chased them very often and I have frightened them. And I then wanted to eat them. I just wanted to crush them. And I regretted it. That day. What I did. Then I saw what I had done. And I was ashamed of myself. So hard that I felt a bit alone.*
> *[Parent: Then you felt alone. Right honey?]*
> *Ben: [unintelligible] Then I walked back home. Alone and sad. And without friends.*

3.2 Thoughts and feelings about activities

Almost all children talked about activities they valued one way or the other. That valuation could differ very much from child to child, also depending on what features of the activity that were considered.
Interestingly, all children talked about the support they were getting in engaging in activities. Sometimes even elaborating on how it affected their engagement and satisfaction.

Features of the activity

An activity is considered good or fun when it contains one or more tasks they like to do. That would often be activities that match their competence or where they even excel at. Also, creative activities that allowed them to be proud of the resulting product received a lot of praise. Or just activities where they could enjoy beauty and rest like watching bees, enjoying the shape of words or enjoying some peace and silence in the couch. Activities that posed limitations were considered not as enjoyable. Like not being able to take all your toys with you on vacation.

> *Researcher: What do you think of [the rehabilitation centre]?*
> *Minnie: Fun fun fun. Sometimes boring boring boring. True, isn't it?*
> *Researcher: Yes. What makes it fun?*
> *Minnie: Sometimes games.*
> *Researcher: And what makes it boring?*
> *Minnie: If I must do some work. All boring. (...) All boring work.*

Context of the activity

Activities were more fun when they could be done in the dark. That would make it more exciting or cosier. Or when they could be done within a beautiful scenery like at the seashore or in a forest. They were less fun when it was cold outside or raining. Or when mandatory activities had to be done while others were doing preferable activities.

> *Bent: I like it there, because there ... Actually, godfather lets us play in the hall. And I like playing in the dark.*

[Parent: Do you like that [additional support lessons] with teacher [name]?]
T-Rex: Yes.
[Parent: But not always right?]
T: But not always.
[Parent: With teacher [name] it is often during the school break. (...) And then the teacher says "And then T-Rex gives a deep sigh. But then it's okay and he'll participate eagerly.". That's T-Rex.]

Purpose to which the activity contributes

Activities could also be valued based on how they contributed to a specific purpose or goal of the child. It was striking how often children would mention that activities were fun because they learned new skills from them. Other motivations were being healthy or getting a reward after completing several activities.

Researcher: What's nice about the scouts?
Bent: There you learn gymnastics. You learn to become strong there.

Researcher: What do you like about sports?
Batman: That I can sweat a little bit. And I also have to go for a drink. Because that's good when I sweat. Then that fat is a bit out of me.

Interactions with others

Most of the children also valued activities based on the interactions they had with others. Some enjoyed simply being together. Others preferred doing activities alone. They appreciated input from others and enjoyed appreciation they received for their own input. Sometimes they were bothered by the input of others and other times by the lack of input.
They talked about their pleasures and annoyances when collaborating, competing, sharing, arguing, and so on.

Researcher: Ah. You don't like brushing your teeth. What is not nice about that? (...)

Lientje: Then she [sister] wants the same toothpaste as me. But if she does it in her mouth, she wants that other paste again ...

Researcher: Ah, so you do not like to share toothpaste then?

Lientje: No.

Researcher: You often read, do you? What is so nice about reading?

Filouke: Yes. Uhm ... Actually, that was mom's book. That she was reading. But I just look at the drawings.

Researcher: You do that together? What is the best? Reading by yourself or reading together?

Filouke: Yes. Reading together.

Researcher: Why is that more fun?

Filouke: Because mommy can read me a story and I can look at the drawings.

Features of activity materials

Also, materials used in activities have an influence on how the activity is perceived. The look and sound of the object could often generate more interest in some children.

Researcher: What's fun about sword fighting?

Ben: You have to beat each other. It can sabre ... That sound.

[Parent: His saber gives off a sound.]

Researcher: And why did mommy take that picture?

Lientje: Because I like to play with the magnets on the fridge.

Researcher: And why?

Lientje: Because that makes a very crazy sound.

Support

All the children mentioned some sort of support they were getting in engaging in activities. Mostly by adults or material aids, but in exceptional cases also by other children.

Material aids could take the form of visualisations for objects, structure of the day, feedback of their behaviour, reward schedules, and so on. They could also be things that assisted or compensated a certain skill, like using a computer to write, or provide emotional support in stressful situations, like a teddy bear or simply a pillow.

> *Beyblade: Since I've been working on the computer, I have not had a single mistake in any homework.*
> *Researcher: What do you think of that? Or how do you feel about that?*
> *Beyblade: Nice. Good.*
> *Researcher: How is that?*
> *Beyblade: Because I haven't made a single mistake.*
>
> *Mortis: I have stingy toothpaste. That is stingly sting. And that's Lanterfant. *Points to the wall.**
> *[Parent: That's his schedule to brush his teeth.]*
> *Mortis: Yes, then you have to brush. And until the ... after ... if you've done cheese, you have to spit out.*
> *Researcher: So you look at the pictures to brush your teeth? And it's called Lanterfant?*
> *Mortis: Yes. Brushing teeth is fun.*

Adults could support in the same way. Offering emotional support, helping the child perform a task or taking on parts of an activity where the child still lacked the needed skills. They can also assist in planning activities, helping to make choices and solving problems.

Bent: And mom is also important to me. When we fight, mom can solve it.

Beyblade: I have not made a mistake yet. But I have a secret weapon for that. (…) My mom.
Researcher: Your mom is your secret weapon. That's nice. And what makes her your secret weapon?
Beyblade: If I do not know something, I ask her.

One child also mentioned the support she gets from fellow classmates to cope with stressful situations

[Parent: Why do you like sitting next to [classmate]?]
Lientje: That I can fiddle with her hair.
Researcher: And what do you think of that? That she allows it.
Lientje: Nice.
Researcher: And what does [classmate] think of that?
Lientje: Fine. (...) That she helps friends instead of being bothered by it.

3.3 Connections between themes

Some of the anecdotes of the children pointed out that the above-mentioned themes are strongly interconnected. Some thoughts would heavily influence satisfaction with the activity, like not enjoying a birthday party because the people in costumes are scary.
Some strong emotions would bypass other themes to directly result in an activity like getting under the blankets when you're scared or making a drawing when you're sad.
And there were also anecdotes where a bad fit between the skill requirements of a certain activity and the activity competence of the child would most of the times result in a lack of satisfaction and often frustration.

Lientje: I think those dolls [dressed up people] are scary when we have a
birthday. Because always when we have a birthday, those dolls come. (...)
[Parent: That is very difficult.]
Lientje: Yes. Because sometimes they also dress up in a doll.
Researcher: And that's scary then. (...)
Lientje: Because then I do not see who that is. And if they do not have a hole
here [face] ... who that is.

3.4 Mediators

All children spoke about mediators for participation in one way or another.
These are persons or things that have an influence on the interaction between
some of the themes.

Access to activities

The children often mentioned gatekeepers or facilitators to access to activities.
Other people provide access to activities or make it completely impossible. The
biggest influence were the parents who would allow certain activities or certain
friends or would impose rules and conditions on doing certain activities. Parents
also provide access to activities by making arrangements and paying for
activities.

Researcher: Ben. Can you do anything that you want to do?
Ben: No. I can't watch Kadet. That is prohibited. Not anymore.
[Parent: Why has mommy banned Kadet?]
Ben: That's not good for me.
[Parent: That makes you very restless.]

Researcher: Ah, you play football there?
Nardas: No. Mom says if I can swim, only then I can play football. Because I
must learn to swim first.

Also, other children were gatekeepers to certain activities by allowing or excluding them from group activities or providing access to materials they owned.

> *Researcher: And what can't you do?*
> *Mortis: Playing with something different from [sister].*
> *[Sister: Not always.]*
> *Researcher: Sometimes you want to play with [sister]'s things, but she doesn't allow it.*
> *Mortis: Yes, sometimes. (..)*
> *[Parent: That's because ... [sister] has a few of those craft books for real girls. To design things and stuff. And those are not booklets where you can simply colour and so on. So that's why we created a personal drawer.]*

Context factors were mostly discussed as a possible obstacle to access to activities. Like not having the right materials or tools to do activities or not being able to do outdoor activities because of bad weather.

> *Filouke: If it rains you can't cycle outside. That is not fun. And when it snows, you can't go into the pool.*

Personal factors could also be an obstacle to accessing some activities. Like age restrictions on activities, not having developed the activity repertoire to do something or simply being ill.

> *[Parent: What's hard for you T-Rex? What would you like to do, but you say it is too difficult for you?]*
> *T-Rex: Making toys alone.*
> *[Parent: But that is still very difficult. Repairing toys.]*

*Beyblade: Actually, I'll be allowed to work at the petting zoo when I'm sixteen.
(...)*
Researcher: What's fun about that?
*Beyblade: Euh ... Making a lot of money. And then I will spend all that on
Beyblades. But also, on a television for my room.*

Appreciation of others

All children would also choose or try to avoid activities based on the people
involved regardless of the kind of activity. Reasons would be because they have
a shared history, or because they consider them funny or bothersome, or just
because they often do things together. Having a significant other to do an
activity with would often overrule the importance of a good match between child
features and activity features. Or the presence of an unwanted other would
undermine a good match between child and activity.

> *Ben: There's a child in my class who screams. And she says I'm naughty. And
> that's not true. And I want her away from school. It's a girl. And she spits on the
> chair to make it clean! And she screams when you raise your finger!*

> *[Parent: And what do you think of [classmate]?]*
> *Noem: That she's sweet. (...)*
> *Researcher: How do you know that she is sweet?*
> *[Parent: Why do you like her?]*
> *Noem: Because she wants to do everything. (..) If you say something, she
> allows [classmate] it.*

<u>Appreciation by others</u>

Lastly, others also function as mediators of the influence of activities on the satisfaction and self-awareness. Feedback from others influenced their perception of activities and themselves.

> *Bent: *Points to a work of art on the windowsill.* That one's mine. (...) And mom asked "Whom is that?". And mom did not believe me. I drew those teeth. And mom liked that so much. And she did not know that was mine.*

3.5 Thematic map

By grouping related themes together, visualising connections with arrows and mediators as gates, the data can be presented as follows.

Figure 4: Thematic map of the lived experience of participation
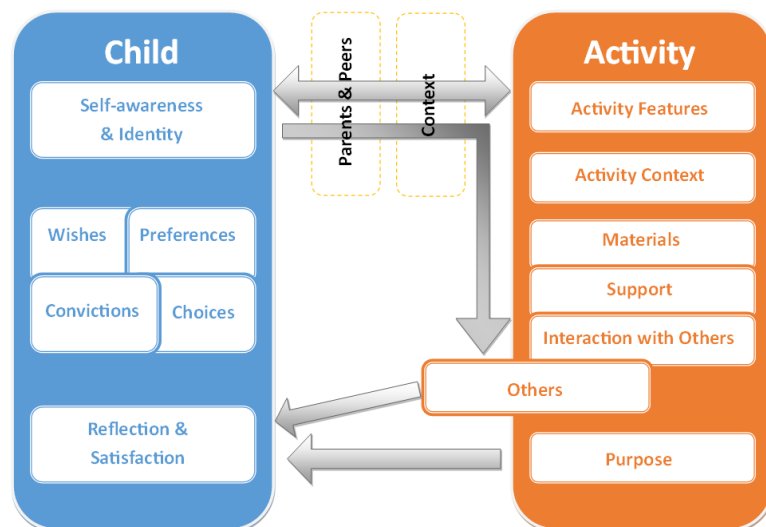
The figure represents the subjective aspects of participation of young children with ADHD, ASD and/or DCD. For successful participation to result there must be a good match between child subthemes and activity subthemes. When activities can be done with important significant others, a good match between child and activity is optional. Context factors, parents and peers are represented in the figure as supports or obstacles to access to activities and therefore participation.
Satisfaction with the activity in turn, results from a good match between child and activity and appreciation by others.

4 Discussion

4.1 Concerning findings

4.1.1 Research results within the wider theoretical context

The results generated by this study add to the understanding of the child's subjective experience of participation, adding to the validity of the construct of participation used in research and clinical practice.

Compared with the findings of Imms et al. (2016), multiple similarities and overlapping themes can be observed. The child subtheme of "Self-awareness and identity" can be matched to the theme of "Sense of self" described by Imms et al. as "intra-personal outcomes of participation related to confidence, satisfaction and self-esteem". The child subthemes "Convictions, wishes, preferences and choices" show overlap with Imms' subtheme of "Preferences", described as "the opportunity to choose and to be able to undertake activities that are meaningful or valued". Activities that are valued and meaningful are described in occupational therapy as occupations.

When the subjective layer of the above mentioned activity subthemes is added to Imms' subtheme "Involvement", "the experience of participation while attending, including elements of motivation, persistence, social connection, and affect", the term "Occupational engagement" would be more fitting. Christiansen and Townsend (2010) describe Occupational engagement as "Full participation in occupations for purposes of doing what one needs and wants to do, being, becoming who one desires to be, and belonging through shared occupations in communities."

As suggested by Imms' thematic map "Activity competence", "the ability to execute the activity being undertaken according to an expected standard", results from participating in activities. The data from this study suggests adding "Occupational satisfaction" as a co-concurring result, described by Christiansen and Townsend (2010) as "contentment with occupations".

The data from this study suggests that not only does participation happen within a frame of context factors, as depicted in the thematic map of Imms, but those factors also function, together with parents and peers, as gatekeepers or mediators to participation in activities.

The need for a good match between the child factors and occupation factors (an activity within a certain environment) fits well with the Person-Environment-Occupation model (Law et al., 1996) that states that optimal occupational performance results form a good match between the person, occupation and environment.
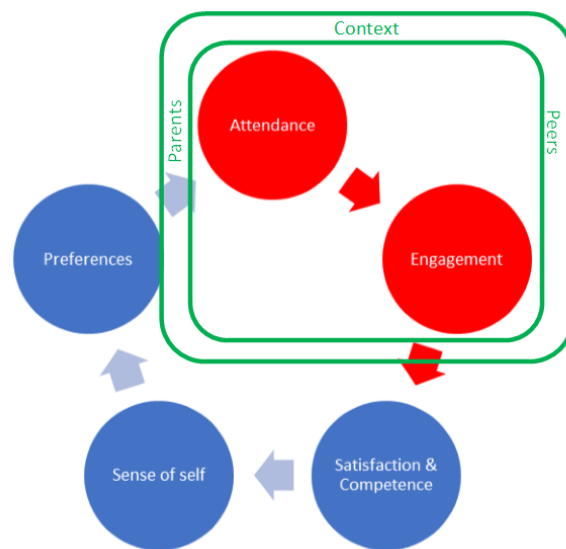
Figure 5: Updated thematic map of children's participation

4.1.2 Unexpected findings and considerations

During the accumulated one hour and a half interviews the participating children would not mention a lot of obstacles to participation. When asked specifically for obstacles they often needed help from parents to find any. This would suggest they experienced little obstacles to successful participation at the time, possibly thanks to the vast support of the parents.

Since the interviews were aimed at the child, little data was gathered on the perception of the parent. But the limited data would suggest parents experience more obstacles to the participation of their child than the children themselves. Further comparative research on both perception could confirm or disprove this suggestion.

During the current study a new research project on the participation and needs of children with DCD (Jasmin, Tetreault, Lariviere, & Joly, 2018) was published that did exactly that. And they have found indeed that both perceptions differ in that aspect.

This would suggest that clinical interventions for children with DCD, but also ASD and ADHD, should not only be aimed at the children, but also at the needs of the parents. Jasmin et al. (2018) suggest indirect interventions, such as training and coaching for parents.

Since publication of the ICF (WHO, 2001, 2007), healthcare provides are more focussed on participation as a health outcome. The children participating in this study did not explicitly mention the impact of providers on their experience of participation. The perception of children on the received healthcare services would therefore be an interesting topic to further explore.

Also noteworthy, ten of the sixteen children mentioned occupations resulting in the attribution of roles and identities in one way or another. Most often children would mention that playing together often results in the other person being your friend. More research on the interplay of occupation, identity and roles would shed more light on the topic.

4.2 Concerning methodology

This study consulted the guideline for research with children with disabilities from Whyte (2005) because it offered practical tools and advice to consider in creating the research protocol. But there are many other guidelines that could be used in preparation for similar research (Curtin, 2001; Phelan & Kinsella, 2013; Shaw, Brady, & Davey, 2011). A comprehensive comparative study of these and similar guidelines would aid the process of selecting the guideline most fit for different paediatric research projects.

4.2.1 Participatory research

Every visit parents and children were asked for feedback and suggestions for improvement within the research.
Most children enjoyed the interviews and the camera assignment. Often because they could show things and talk about themselves. Others really appreciated the drinks and snacks the researchers brought along for the interviews. Parents often confirmed the child loved the attention they were getting during the research.

One participant had a lot of trouble focussing on the conversation. His need for a clear structure of the interview, resulting from his attention disorder, was in strong contrast with the characteristics of an open interview guided by the child. He often left the conversation to do something else to then be called back by his mother or the researcher. He often asked to stop the interview. But when asked if he wanted the researcher to leave he indicated that he enjoyed the conversation and wanted the researcher to stay. Eventually all three interviews were fully conducted.

Some parents and one child mentioned the questions were sometimes too hard for the children. The phrasing or wording of the question was sometimes too abstract. Parents suggested to use visualisations to help the child understand the questions.
Parents also mentioned the child sometimes was hinting to thoughts or feelings in talking about their participation. These were sometimes hints or signals the researcher didn't notice because of lack of background information the parent did have. Therefore, some parents suggested to use the parents as both an interviewee and co-interviewer in the interviews. A suggestion the researchers put into practice very early in the data collection phase. Input of the parents was used to elicit more information from the child. Researchers were sure to always ask the child to confirm, contrast or nuance the input of the parent.

Another suggestion of one of the parents was to start the second interview with the most recent picture the child had taken. This would help the recollection of thoughts and feelings and would result in richer data. A suggestion the researcher also put into practice early in the data collection phase.

Some parents gave the feedback that the camera assignment sometimes drew too much attention to the child, which in some cases was considered a disturbing or stressing factor in school or at home. One child mentioned the use of the camera at school resulted in too much unwanted attention.
Often parents deleted some pictures that were not fit for people outside of the family. Something that the child often found a pity.
No solutions were found for these experienced inconveniences.

Some parents found the informed assent to be a lot of information but very useful to help the child predict what was to come. This predictability offered structure and peace of mind for the child. Though one participant found it hard to say goodbye at the end of the last interview, likely resulting from difficulties in coping with transitions related to autism spectrum disorder. She cried and did not want the researcher to leave. So, the end of the research could still be better announced or emphasized, to further enhance the predictability of the interview sessions.
One child was confused because only one of the researchers visited to do the interviews. This could also be better emphasized in the informed consent.

One parent gave the suggestion to do further research into the experience of siblings on living with a brother or sister with developmental disabilities.
Children and parents also gave suggestions for the dissemination of the result of this research. They found it useful to translate the results of the study to a children's story which contains some profiles of the children.

Reflecting on the input in and influence on the research the children and parents had, the level of participatory research could be situated at level six of the Ladder of Participation of Hart (1992): Researcher-initiated, shared decisions with children and parents. Since children were not consulted before the start of the study, the initiative for the research came entirely from the researchers. But, as mentioned, children and parents had a distinct influence on decisions during the research project.
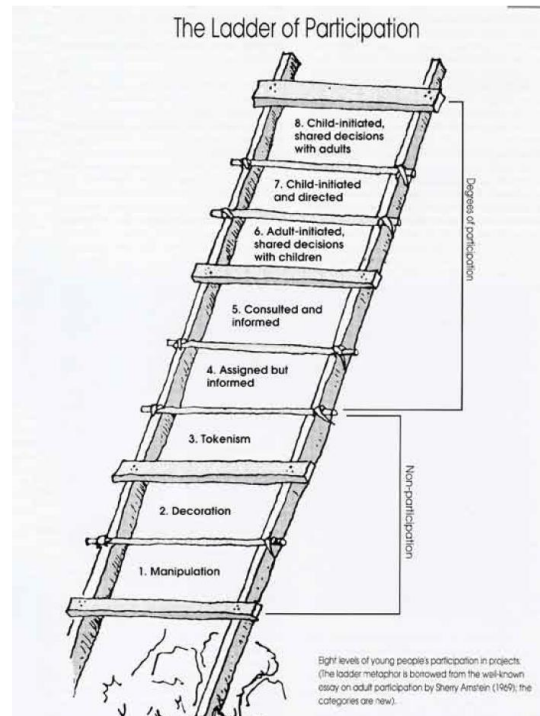
Figure 6: The ladder of participation (Hart, 1992)

4.2.2 Limitations of the study

The age of the participants was limited from five to eight years old. The research of Jasmin et al. (2018), where children up to thirteen years old could participate, found similar results (see discussion of findings). There is a possibility that by growing older the differences between children's perception of their participation and the perception of their parents narrows. But this calls for further research.

Another suggestion would be to compare the lived experience of this population with the experience of typically developing children or children with physical disabilities.

The research did not do in-group comparison of the perception of children with ADHD versus ASD versus DCD versus a combination of disorders. This could be the subject of a second analysis of the obtained data within this study.

And there was no data obtained on the parent's education, socio-economic status and other possibly influencing factors. A possible correlation between these factors and participation could be another hypothesis for further research.

4.3 Implications for research and clinical practice

The results of this study contribute to a deeper understanding of the subjective experience of participation of young children with developmental disabilities and thereby adding to the construct validity of the concept of participation.

A clear and uniform construct description of participation encourages the development of a coherent scientific body of knowledge in rehabilitation research on the one hand and valid assessment tools and effective interventions in paediatric rehabilitation on the other hand.

When concluded that parents experience more needs concerning the participation of their child than the children themselves, more parent training and coaching interventions are advised. The data of this study for example suggests that parent coaching in matching activity factors with child factors and removing contextual obstacles to participation would result in more access to activities and higher occupational satisfaction.

5 Conclusion

This study showed it is possible to elicit children's views on their own participation. By adapting the informed consent to the language and communication styles of young children, they were provided with the possibility of giving full assent to participation in the study. Using open interviews with the child and parent, supported via a camera assignment, generated a lot of rich data on the subject.
Children discussed themes related to their person, activities and connections and mediators between those themes. These themes fit well within earlier and recent research on the subject of participation and within the wider theoretical framework of human occupation. The insights from the study add to a more valid construct of participation that can be used in paediatric rehabilitation and in assessment and interventions in clinical practice.

The study also confirmed children and their parents can be active participants in research (Curtin, 2001). Both gave meaningful feedback that immediately could be used to adjust the research protocol and generate more valuable data. By participating so actively they have made a substantial contribution to the expansion of the knowledge base of occupational therapy.

Conflict of interests

The authors declare that there is no conflict of interest.

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Appendix

- Appendix 1: auteursrecht
- Appendix 2: Recruitment poster
- Appendix 3: Information form phone call
- Appendix 4: Informed consent
- Appendix 5: Informed assent
- Appendix 6: Interview protocol
- Appendix 7: Accompanying letter to the camera assignment

Appendix 1: auteursrecht

"De auteur en de promotor geven de toelating deze masterproef voor consultatie beschikbaar te stellen en delen ervan te kopiëren voor persoonlijk gebruik. Elk ander gebruik valt onder de beperkingen van het auteursrecht, in het bijzonder met betrekking tot de verplichting uitdrukkelijk de bron te vermelden bij het aanhalen van resultaten uit deze masterproef."

Datum

Birger Destoop   dra. Marieke Coussens   dr. Dominique Van de Velde

Appendix 3: Information form phone call

Indien niet via URL

Naam ouder	
Naam kind	
Geboortedatum (en leeftijd j&m)	
Adres	
Telefoonnummer	
E-mailadres	

Toelichting vooraf
- Onderzoek wil nagaan hoe kinderen hun deelname aan het gezinsleven, school, buurt enz. beleven. Dit willen we doen aan de hand van 3 interviews van 30 minuten bij jullie thuis. Tussen interview 1 en 2 geven we (kind) een camera mee om zo ook een visueel beeld te scheppen op zijn participatie.
- Vragen? Bedenkingen?
- We sturen u op voorhand verdere toelichting bij het onderzoek op. Eén versie voor u als ouder en één versie voor (kind). Is het mogelijk dit al eens te overlopen met (kind)? Zo heeft (kind) tijd om hierover na te denken. Bij het eerste interview bekijken we het nog eens samen en kunnen jullie zich al dan niet akkoord verklaren.

Enkele vragen om te checken of jullie passen binnen onze onderzoeksdoelgroep:

Meest gebruikte taal (kind) thuis? Nog andere manieren van communiceren? (non-verbaal, tekenen, …)	
Diagnose? Door wie?	
Intelligentietest afgenomen? Door wie?	

Enkele vragen die zullen zorgen voor een vlot verloop van het eerste bezoek:

Heeft (kind) een manier waarop hij/ze liefst of meestal vreemden begroet? Is er een houding dat ze gewoonlijk aanneemt t.o.v. vreemden? (verlegen, …)	
Wat is voor (kind) een leuke activiteit om een eerste contact te leggen? Is het mogelijk om een tekening of foto in de buurt te leggen waar (kind) iets over kan vertellen?	
Kan u (of partner) aanwezig zijn gedurende alle interviews?	
Kunnen we voor het interview gebruik maken van een rustige ruimte in het huis?	

Praktische vragen:

Voedselallergieën of andere zaken waar we best op letten als we een drankje of een knabbeltje meedoen?	
Data en tijdstip van de 3 bezoeken. **Let op:** telkens een week tussen.	

Nogmaals vermelden:
- We sturen u via mail bevestiging van de 3 afspraken.
- Informatie via post en mail. Graag eens doornemen met kind.

Appendix 4: Informed consent

Informatiebrief ouder

Beste,

Graag hadden wij u de toestemming gevraagd om uw kind te laten deelnemen aan een onderzoek (Belgisch Registratienummer: B670201835100) georganiseerd door de Vakgroep Revalidatiewetenschappen en kinesitherapie aan de Universiteit van Gent.

Wat belangrijk is om te weten

Inhoud en verloop van het onderzoek

Uw zoon of dochter neemt deel aan een onderzoek rond participatie (deelnemen aan het dagelijkse en maatschappelijke leven zoals op school meespelen op de speelplaats, meedoen in de klas, in de turnles, …) van 5 tot 8-jarige kinderen. Hierbij willen we nagaan hoe uw kind zijn/haar eigen participatie beleeft. Deze inzichten kunnen dan bijdragen aan onderzoek naar interventies die deze participatie trachten te vergroten.
Dit onderzoek doen we aan de hand van 3 interviews van maximaal 30 minuten die bij u thuis zullen plaatsvinden en 1 fototoestel-opdracht die uitgevoerd zal worden in de dagelijkse omgeving van uw kind. We vragen hierbij ook uw aanwezigheid bij de interviews.

Tijdens het eerste interview leren we elkaar kennen en bevragen we uw zoon/dochter omtrent de activiteiten die hij/zij (graag) doet. Tussen interview 1 en 2 lenen we uw kind een fototoestel uit waarbij we vragen om foto's te trekken van alle handelingen die uw kind onderneemt (ochtendroutine, activiteiten op school, naschoolse en vrijetijdsactiviteiten, deelname aan gezins- en familieleven, …). Deze foto's worden het gespreksonderwerp van het tweede interview en zijn nadien uw eigendom. Er zal uitdrukkelijk om uw toestemming gevraagd worden indien men een van de foto's wenst te gebruiken als illustratie bij het onderzoek. In het derde interview toetsen we af of we alles goed begrepen hebben en of uw kind nog aanvullingen heeft.

De drie interviews worden opgenomen op video om ook non-verbale communicatie te kunnen registreren. Het videomateriaal wordt na elk interview uitgetypt.

Indien u beslist om deel te nemen aan het onderzoek, vragen wij u vriendelijk het toestemmingsformulier hieronder te dateren en te handtekenen. Deelname aan het onderzoek gebeurt op een volledig vrijwillige basis. Dit betekent dat u op elk moment tijdens het onderzoek kunt beslissen om de deelname stop te zetten.

Bescherming van u, uw kind en uw gegevens

Indien u het toestemmingsformulier ondertekent, gaat u er mee akkoord dat de onderzoekers toegang hebben tot de vertrouwelijke informatie verzameld tijdens de studie. In overeenstemming met de Belgische wet van 8 december 1992 en de Belgische wet van 22 augustus 2002, zal uw persoonlijke levenssfeer worden gerespecteerd en kan u toegang krijgen tot de verzamelde gegevens. Elk onjuist gegeven zal op uw verzoek verbeterd worden. Uw persoonlijke gegevens worden geanonimiseerd (gecodeerd). Dit wil zeggen dat er een letter- of cijfercode wordt gebruikt die enkel door de onderzoeker(s) kan teruggekoppeld worden aan uw naam. Uw identiteit wordt echter op geen enkel moment openbaar gemaakt, ook niet bij de publicatie van de resultaten van het onderzoek.

Uw deelname aan het onderzoek, alsook uw eventuele beslissing om deze deelname stop te zetten, heeft geen enkel gevolg voor u of voor uw kind.

Gevolgen van het onderzoek

Er zijn geen risico's verbonden aan uw deelname aan het onderzoek. De studie werd reeds goedgekeurd door het Ethisch Comité voor Wetenschappelijk Onderzoek van de Faculteit Psychologie en Pedagogische Wetenschappen van de Universiteit Gent en de Privacycommissie.

Hoewel het niet te verwachten valt dat er ook maar enige schade zou voortvloeien uit deelname aan deze studie, is toch een foutloze aansprakelijkheidsverzekering afgesloten. Dit in overeenstemming met de experimentenwet van 7 mei 2004.

Deze studie bezorgt u geen extra kosten.

Tijdens het onderzoek zullen u en uw kind de mogelijkheid hebben om mee te beslissen in welke vorm de resultaten van de studie zullen gecommuniceerd worden. Na afronden van het onderzoek wordt u op de hoogte gebracht van de resultaten.

Ter compensatie van uw deelname aan dit onderzoek, wordt een kleine attentie voor het kind voorzien.

Contactgegevens

Indien er nog onduidelijkheden zijn omtrent het onderzoek of omtrent uw rechten en plichten; in geval van vragen, klachten of opmerkingen; kunt u altijd bij volgende contactpersonen terecht:

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INFORMED CONSENT

Ik, ondergetekende,

…………………………………………………………………,

ouder/voogd van

……………………………………………………………geef hierbij de toestemming om mijn kind te laten deelnemen aan het onderzoek aan de vakgroep Revalidatiewetenschappen en Kinesitherapie een onderzoek aan de Universiteit Gent. Ik verklaar dat ik

1. de uitleg over de achtergrond, doelstelling en het opzet van dit onderzoek heb gelezen en dat mij de mogelijkheid werd geboden om bijkomende informatie te verkrijgen.

2. volledig uit vrije wil zelf deelneem aan het wetenschappelijk onderzoek.

3. de toestemming geef aan de proefleider om de resultaten op anonieme wijze te bewaren, te verwerken en te rapporteren.

4. op de hoogte ben van de mogelijkheid om de deelname aan het onderzoek op ieder moment stop te zetten. Dit zal op geen enkele manier invloed hebben.

5. ervan op de hoogte ben dat ik, nadat de studie is afgerond en de resultaten bekend zijn, op aanvraag, een samenvatting van de onderzoeksbevindingen kan bekomen.

6. op de hoogte ben van het feit dat alle gegevens voortvloeiend uit dit onderzoek kunnen gebruikt worden bij verdere gelijkaardige onderzoeken, die het onderwerp zullen zijn van een aparte aanvraag bij het ethisch comité.

Gelezen en goedgekeurd op ……………………………. (datum),

Handtekening

□ Ik wens dat de beelden van het interview niet gebruikt worden voor verdere onderzoeksdoeleinden.

Dit ben ik(/is Marieke). Ik ben(/Marieke is) een onderzoeker. (Birger: Ik ben ook een onderzoeker.) Onderzoekers denken veel na. Marieke en Birger ook. Wij weten iets niet. Wij willen weten wat kindjes doen. Wat doen ze thuis? Wat doen ze op school? Dat willen we aan kindjes vragen.
Zo worden we slimmer. Zo kunnen we kindjes helpen. Helpen om leuke dingen te doen.

Ik vraag dit graag aan jou. Ik kom met je praten. Dat doen we hier. Bij jou thuis. 3 keer.

Vandaag is de eerste keer. We doen iets leuks. Jij mag kiezen. En we praten. Jij mag vertellen wat jij graag doet.

Daarna krijg je een camera. Jij mag dan foto's trekken. Van alles wat je doet. Thuis, op school, bij familie, …

Dan kom ik terug. En praten we over de foto's.
Die foto's zijn dan voor jou. Misschien neem ik graag ééntje mee. Maar dat vraag ik dan aan jou.

Zo hebben we al twee keer gepraat. Dat nemen we allemaal op. Dit doen we met de telefoon.

Dan kan ik dit thuis bekijken. Ik schrijf dan op wat je vertelde.
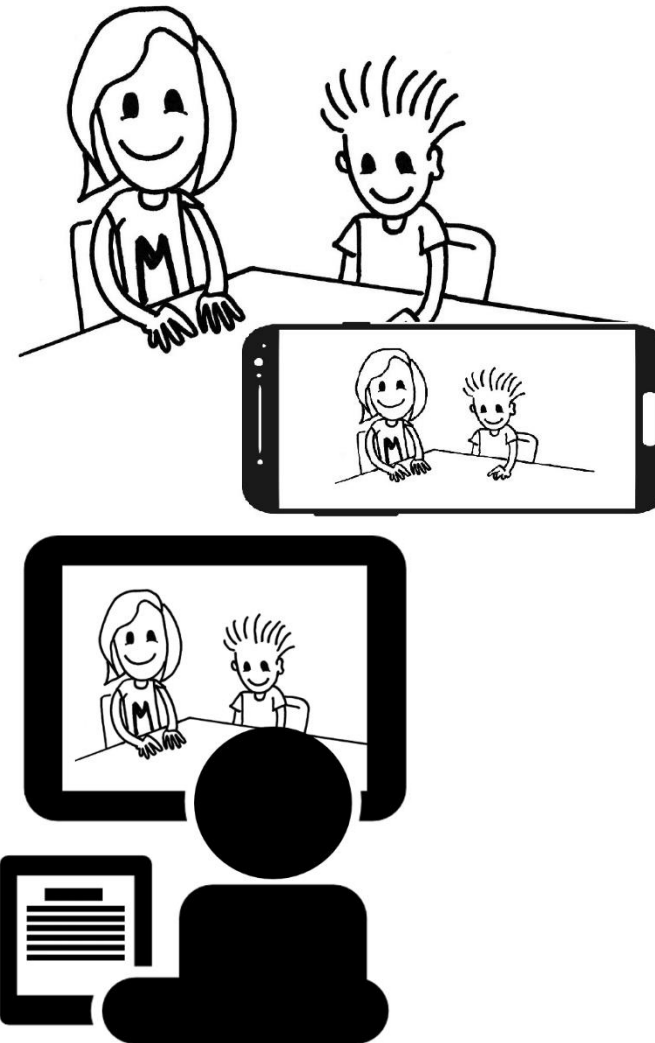
Dat neem ik mee de laatste keer. Ik zeg wat jij vertelde. Jij zegt of het juist is. Wat fout is maken we juist.

Straks vraag ik of jij wil helpen. Dat kan jij kiezen. Misschien wil jij met mij praten. Dan schrijf je straks je naam. Zo zie ik dat jij wil helpen.

Misschien wil jij niet praten. Dan ga ik terug naar huis. Dat is niet erg.

Volgende (week/keer) kom ik nog eens praten. Dan mag jij opnieuw kiezen. Dan praten we over foto's. Of misschien wil je niet. Dat kan je zeggen. Dat is niet erg. Jij mag elke keer kiezen.

Ik schrijf dus op wat je vertelt. Ook wat andere kindjes vertellen. Ik weet wie je bent. Andere mensen niet. Dat is een geheimpje voor ons.
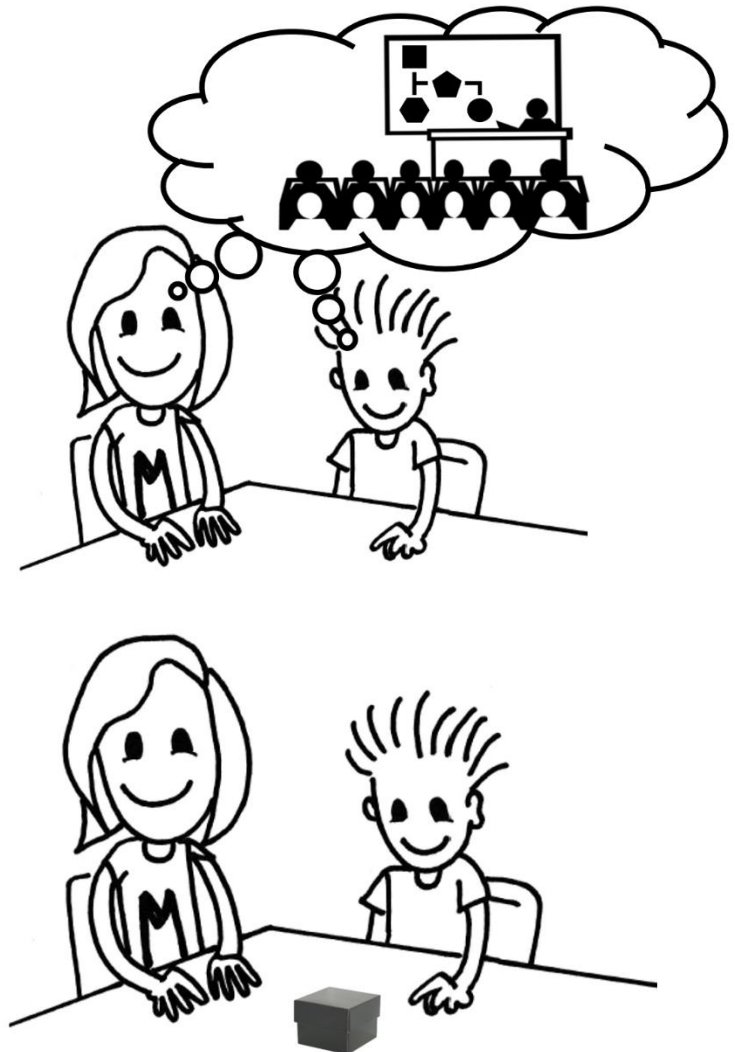
Er kan niets ergs gebeuren terwijl wij praten. Daar hebben slimme mensen over nagedacht. Ik vroeg of ik met jou mocht praten. Dat vonden zij goed.
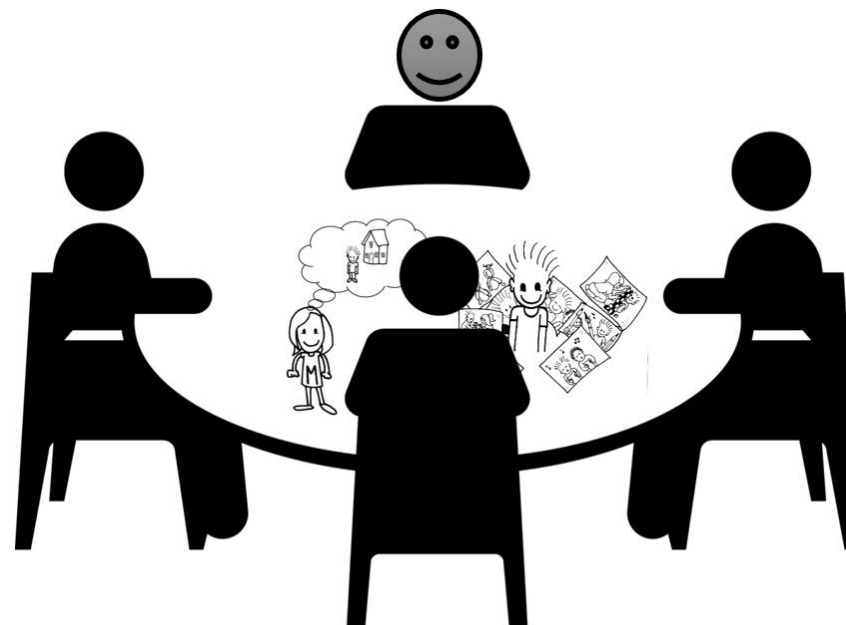
Na 3 keer praten stoppen we. Dan zijn we klaar. Dan ben ik slimmer. Dan vertel ik verder wat ik leerde. Jij kan dan helpen. We denken na wat ik kan vertellen.

Ik ben blij als je helpt. Dan zeg ik "dank u" met een heel klein cadeautje.

Dit zijn wij. Misschien wil jij iets van mij weten. Dat mag je altijd vragen. Ook als ik er niet ben. Mama/papa kan mij altijd bellen. Of een brief schrijven. Jij kan ook bellen. Dat vraag je maar aan mama/papa.

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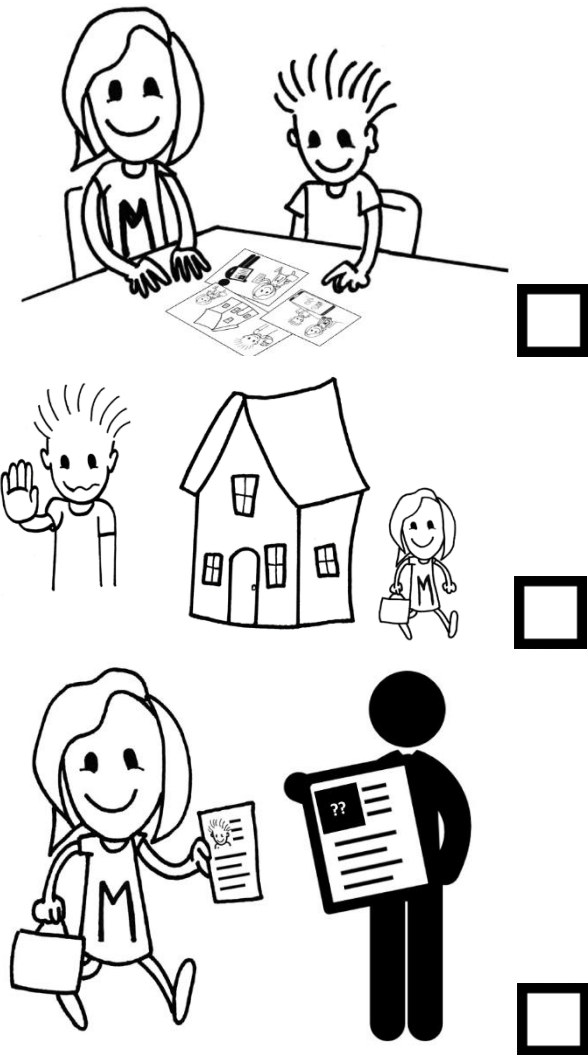(Tel: 09/332.12.18) Marieke.cousens@ugent.be

Hier mag je in de vakjes kruisen.
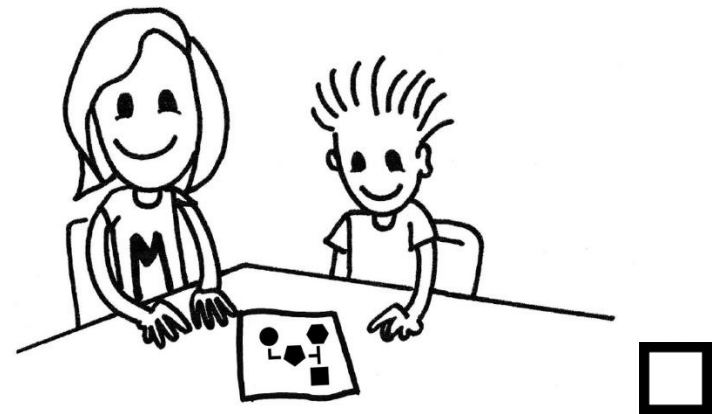
Heb ik alles goed verteld? Heb je het begrepen?

Wat staat hier? (Vind je het niet leuk? Dan mag je stop zeggen. Dan ga ik weg. Dat is niet erg.)

Wat staat hier? (Enkel ik weet wie je bent. Dat is ons geheimpje.)

Weet je graag wat ik van de kindjes leerde? Dat mag je vragen. Dan geef ik dat aan jou.

Wil je me helpen? Dan mag je hier je naam tekenen.

Appendix 6: Interview protocol

Composed following the guidelines and advice of Whyte (2005) and Curtin (2001).

First visit (30'): Getting to know you
- Greet the child (and the parent) in its preferred way.
- Provide a drink for the child and parent.
- Explain the research project, visits, camera assignment and informed consent.
  - Provide written informed consent for the parent to follow and sign.
  - Explain to the child in an age-appropriate language use
  - While the parent overhears
  - Use props to help explain
  - Encourage the child and parent to ask questions.
  - Ask the child to articulate its understanding of the research.
- Ask the child where everybody should sit and if it wants to help set up the camera. (overcoming inequality)
- Start the preferred activity
  - Ask the child (if it wants) to talk about the picture or drawing. (overcoming inequality: giving a position of expertise)
- Interview questions: Let the child guide the conversation. When the child stops talking, ask open questions to encourage it to elaborate on its experiences. Let the child select what question (visual aid) to answer. (overcoming inequality)
  - Tell the child that every answer is a good answer. You know absolutely nothing and really want to hear what the child thinks. (examining beliefs & overcoming inequality) But even so it's okay if it doesn't know or want to give an answer.
  - What do you like to do?
  - What did you do today/yesterday/this week?
  - Where? When? How often? For how long? With whom?
  - How does it make you feel?
  - What do you think about that?
  - Tell me more.
  - Paraphrasing the last sentences.
- When the child does not understand or answer the question, first examine your part in this occurrence. For example: asking a vague question. (bridging different styles of communication, examining beliefs: maintaining a non-adult-centric view)
- Games or activities for when the child is shy or demotivated
- Give the possibility of choosing their own pseudonym.
- Ask the child to repeat the camera assignment and give the camera.
- Ask the child and parent for comments on the interview

Camera assignment: You're the photographer
- The child borrows the camera for one week, wears it around its neck or waist and tries to take at least one picture of everything it does.
- Provide an accompanying letter for family members, teachers, leisure supervisor, …

Second visit (30', one week after first visit): Picture time
- Bring a snack for the child and parent.
- Ask the child where everybody should sit and if it wants to help set up the camera. (overcoming inequality)
- Discuss with the child the analysis of previous session. Let them choose their own pseudonym.
- Tell the child that every answer is a good answer. You know absolutely nothing and really want to hear what the child thinks. But even so it's okay if it doesn't know or want to give an answer.
- Tell the child it's okay to notify you when it is tired or bored. If so, have a short break.
- Discuss the pictures taken for the camera assignment. Ask the child what picture to discuss first/next. (overcoming inequality)
  - Encourage elaboration via open questions (using the visualisations)
    - Tell me more about this picture.
    - Where/when/who is this?
    - What were you feeling/thinking at that moment?
    - Paraphrasing the last sentences.
- Ask the child and parent for comments on the interview

Third visit (30', preferably one week after second): Thank you and goodbye for now
- Ask the child where everybody should sit and if it wants to help set up the camera. (overcoming inequality)
- Tell the child it's okay to notify you when it is tired or bored. If so, have a short break.
- Tell the child that every answer is a good answer. You know absolutely nothing and really want to hear what the child thinks. But even so it's okay if it doesn't know or want to give an answer. Cover topics left over from last session.
- Present the child with the data analysis and -synthesis of its interviews. Check if the formulated interpretations are correct.
- Are you happy with what you do / can do?
- What do you want to do more/less/different?
- Can you do everything you want to do?
- Ask for ideas on how to disseminate the findings of the study.
- Ask the child and parent for comments on the interview
- Let the child pick a thank you gift.

Attitude and points of consideration for the researcher
- Examine your own beliefs
  - Maintain a non-adult-centric view. Recognize children as experts about their own lives.
- Overcome inequality
  - Refrain from behaviour that could be interpreted as authoritarian, judgemental or interfering. Don't use judgemental phrases like "that's right" or "that's good".
  - Maintain a responsive versus a dominating stance towards the child.
- Bridge communication styles:
  - Learn the vocabulary and phrase length the child uses. Ask questions that are a maximum of 5 words longer than the child's average numbers of words in a sentence.
  - Refrain from using complex adult language.
  - Keep in mind to use non-verbal conversation techniques.
  - Ask questions about the immediate/observable situation.
  - Develop questions that use words introduced by the child.
  - Use names instead of pronouns.
  - Avoid "why"-questions.
  - Ask the child to repeat the question to check if they understood it.

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Appendix 7: Accompanying letter to the camera assignment

<u>Beste (groot)ouder/leerkracht/begeleider/…</u>

Ik doe mee aan een onderzoek aan de Universiteit van Gent. De onderzoekers weten graag wat ik allemaal doe in een week. Thuis, op school, bij de familie, tijdens vrije tijd, …
Daarom heb ik een camera bij me. Ik neem van elke activiteit een foto. Ik neem zo veel mogelijk foto's. Dan heb ik veel te vertellen wanneer ik de onderzoeker de volgende keer zie. Deze camera zit in de heuptas die ik draag (of meeheb).

Help je mij onthouden om doorheen de dag veel foto's te trekken?
Als ik iets doe waarbij ik zelf geen foto kan nemen, trek jij er dan een?

Dankjewel!

_____