"This is Not Me" – A Critical Discussion About Methodological Issues Concerning Agency and Participatory Sense-Making in Qualitative Research with Children

Wenche Schrøder Bjorbækmo[1] , Anne Greve[2], and Mona Asbjørnslett[3]

Abstract

Participatory sense-making and agency are important methodological issues in qualitative research, especially that involving children. In this article we investigate and discuss how agency unfolds in three specific situations as recorded in the reflexive notes of two of the authors regarding their research with children with various medical diagnosis and disabilities. Using a combined autoethnographic and enactive phenomenological approach, the authors explore three particular moments where child participants registered disagreement with, or rejection of, the application to them of prevailing notions of 'disability'. On the basis of the findings, the authors argue that the process of implementing and performing qualitative research implies a process of participatory sense-making in which participants' multi-level agentic capacity is the basis for understanding one another's gestures and vocal expressions. The article illuminates how different bodies enable different individual embodied, embedded, emotive and enacted agentic expressions, and how power, understood as an extended agentic capacity, circulates in the co-existence between child and researcher in qualitative research. Researchers are urged to develop the willingness and ability to 'dis-place' themselves when working with child participants, so as to move towards the child with interest, respect, and openness to learning from them.

Keywords

phenomenology, qualitative method, children, disability, agency, participatory sense-making, enactive approach, the 5E approach

Introduction and Background

In this article, we examine and discuss methodological issues concerning participatory sense-making and agency in qualitative research with children, specifically those with a medical diagnosis and/or a disability.

"Why do some of our encounters transform us", asks Hanne De Jaegher (2015, p. 112). This question speaks to some of our experiences of doing qualitative research with children. These are experiences we keep coming back to, moments which have left us with questions and unease related to the research process itself and our handling of it.

We understand qualitative research as participatory sense-making encounters, ones that imply the coordination of intentional activity in the interaction. In the process, the meaning-making of the individuals involved is affected and new social meanings can be generated: meanings that were not available to each individual alone (De Jaegher & Di Paolo, 2007, p. 497). Regardless of the manner in which qualitative research is conducted – whether via observation, interview or

[1]Department of Physiotherapy, Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway
[2]Faculty of Education and International Studies, Oslo Metropolitan University, Oslo, Norway
[3]Department of Occupational Therapy, Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway

Corresponding Author:
Wenche Schrøder Bjorbækmo, Department of Physiotherapy, Faculty of Health Sciences, Oslo Metropolitan University, Pb.4 St Olavs Plass, Oslo 0130, Norway.
Email: Wenche.Bjorbaekmo@oslomet.no

other forms of interaction – it remains a participatory sense-making process. It is on the basis of this understanding that we examine and discuss how children's agency unfolds in qualitative research encounters. In particular, we investigate the extent to which children's agency is given the opportunity to be expressed during such encounters, and how it is expressed.

As the basis for this exploratory discussion, we use examples from two qualitative studies where the participants were children with various medical diagnoses and/or a disability. In one study, the aim was to examine how children experience moving and being active in different situations in daily life (Bjorbækmo, 2011). The other study sought to explore how children experience their everyday life, disability, and illness (Asbjørnslett, 2015). In both studies interviews with children and their parents as well as observations were used to generate the empirical data.

Throughout the research process, the researchers wrote reflective notes (hereafter named memos) in which they explored specific events they became particularly concerned with. The memos in which researchers describe and reflect on events during a research project may constitute a hitherto untapped source of knowledge. In our experience, there has been a tendency to view some of these memos as focusing on issues (for example, methodological issues) outside the main purpose of the research project, and for this reason they have received little or no attention.

In this article, however, examples from the researchers' memos actually constitute the core empirical material.

Before we present examples from the researchers' memos and our analyses of these, we present some existing and relevant research concerning children´s agency and qualitative research with children. We then present the theoretical perspectives which guided our exploration of participatory sense-making and agency in qualitative research with children.

Some Relevant Existing Research

The 20th century has been called the age of children´s agency, in the sense that this was the era when children came to be seen as agentic social beings, ones who interpret, make meaning, and make a difference to the social world when given the capacity to do so (Oswell, 2013, p. 36). This perspective is enshrined in the United Nations Convention on the Rights of the Child, which upholds the right of the child to express his or her opinions, 'either orally, in writing or in print, in the form of art, or through any other media of the child's choice' (Article 13.1) (Unicef, 1989). This reflects a growing understanding of children as social agents and actors, with a rightful place in relation to social and political questions (Graham & Fitzgerald, 2010; James et al., 2012; Oswell, 2013).

Such a perspective has implications for the involvement of children as participants in research (Montreuil & Carnevale, 2018). Recognition of children as agents and social actors has resulted in a growing emphasis on carrying out research *with*,

rather than *on,* children, now seen as *beings in their own right, here and now,* rather than simply as future adults in the making (Christensen & James, 2008; Greene & Hill, 2006).

The right of children and young people to participate in research that concerns them is now seen as of vital importance. However, children's right to choose *not* to participate – to opt *not* to assert their agency – has not received the same attention. As Tisdall and Punch (2012) note:

> Children and young people's agency should certainly be a contested and scrutinized concept rather than one which is taken-for-granted, unproblematised or assumed inherently to be positive and desired by all children and young people (Tisdall & Punch, 2012, p. 256).

Conducting research in a way which serves the best interest of children presents various challenges (Grindheim et al., 2020). The same applies to the concept of participatory research with children, an umbrella term which covers both data collection involving children and children's participation in making decisions related to the research process as a whole. No clear guidelines exist for either of these approaches, and the distinction between children's participation as research subjects and their involvement as co-constructors of research remains blurred (Montreuil et al., 2021, p. 1).

Michael Gallagher suggests that children´s 'right' to participation is an ambiguous and even dangerous term, perhaps driven by 'governmentality': a term derived from Foucault, who used it to describe power exercised in the management of groups of people, from families and school classes to institutional hierarchies and in research, all of which need to be problematized (Gallagher, 2008; Gallagher et al., 2010). How children understand, and give informed assent to, participation is considered particularly problematic in relation to children's agency. A research project can be difficult to grasp and understand, and children may feel pressured (by teachers or parents, for example) to give their assent. They may also find it difficult to withdraw once the project is under way (Collier, 2019; Gallagher et al., 2010). Given the growing interest in including children in research, researchers have become increasingly aware of ethical considerations and dilemmas, including the unequal status and power between children and adults (Hill, 2006). Researchers highlight that children should be treated as active agents, and emphasize the importance of ensuring that the children feel safe and respected (Bourke, 2017; Harcourt & Sargeant, 2011; Kjørholt & Winger, 2013; Öneren Şendil & Sönmez, 2020). There is also recognition of the fact that children's interest in a project may be quite limited and that they must be given a clear opportunity to decline or accept participation in an ongoing, negotiated research process (Collier, 2019; Ericsson & Boyd, 2017).

In qualitative research involving children, it appears essential for researchers to reflect on their own perspectives,

beliefs, thoughts, role, capacity for interaction and style – particularly so if they aim to contribute knowledge as to what may support and promote children's active and meaningful participation in research (Montreuil et al., 2021, p. 12).

Daelman et al. (2020) adopt a reflective post-qualitative stance towards the ways in which children and adults may construct their position and/or role in research. They critically explore key incidents (ordinary occurrences that intuitively attracted the researchers' attention) from observational data. Using the theoretical notion of "plugging in", an idea related to the theoretical concepts of "emergent listening, response-ability and becoming-with", they show how:

> These post-qualitative concepts collaboratively imagine ethical practices in research with children, which requires mutual entanglements between participants, gatekeepers, (co-)researchers and ethical committees, among other partners (Daelman et al., 2020, p. 495).

In a critical review, Facca et al. (2020) explore what researchers mean when they use the phrase 'giving children a voice'. They argue that theorizing the 'voice' implies an acknowledgement that the voice is relational, with no authentic or fixed point of origin; a child's voice is almost always produced through intergenerational dialogue. They call upon researchers to attend, explicitly and reflectively, to the methodological implications of their approach, especially regarding the generation and analysis of data.

As early as 2009 Jackson and Mazzei raised questions about how an individual's 'voice' is approached in qualtitative research, in particular the assumption that the voice speaks the truth of consciousness and experience. For Jackson and Mazzei (2009), this suggests a failure to consider the role played by researchers in co-shaping those voices. By offering poststructural perspectives on voice, they interrogate the very notion of what constitutes 'voice'. Which voices does one choose to listen to? Why are some voices accepted as truthful and others not? In a Deleuzian fashion, this anthology seeks in different ways to deconstruct the epistemological limits of voice in qualitative research.

In line with the research presented above, we argue that when researchers use the term 'agency'in research, they need to acknowledge the theoretical understandings which underpin their investigation of agency. A critical examination of children's agency, meaning-making and participation in research therefore appears timely.

In the following section we present our theoretical framework, which is rooted in phenomenology inspired by Maurice Merleau-Ponty and Diana Coole, and phenomenology and enactive theory inspired by Shaun Gallagher and Hanne De Jaegher. This forms the basis for our subsequent analysis and discussion.

Phenomenological and Enactive Perspective

Our point of departure is an understanding of people, regardless of their age and functioning, as body-subjects who are in constant inter-relational exchange with others and the environment they are part of. Our bodily existence implies that we both are and have our bodies. We are both subject and object in the sense that we both see/perceive and experience being seen or not seen; we both hear and experience being heard or not heard. As intentional animated organisms, we are both directed towards, and by, the social, natural, and cultural environment (other people, material realities and a variety of social and cultural discourses) of which we are part (Merleau-Ponty (1962/2002).

As body-subjects, we are always situated in specific situations and contexts; subjectivity is always an intersubjective process (Coole, 2005). For Diana Coole (2005), the notions of subjectivity and individuality are perceived as inseparable from the concept of agency, as well as entwined with ideas about responsibility, autonomy, rationality, and freedom. A phenomenological approach to agency is based on recognizing that it implies "a chiaroscuro of agentic capacities" (Coole, 2005, p. 126). In other words, agentic capacity may emerge in numerous ways within a person's intercorpal lifeworld. Different individuals tend to acquire different agentic capacities, depending on the life they live, the bodies they are and the various situations they are involved in (Coole, 2005, p. 126). Agentic capacity and expression are always embodied. As situated individuals, our corporality (our body) is foundational to our agentic capacity and agentic expression. This has significant implications for detecting an individual's specific agentic capacity and then participating in its mode of expression (Coole, 2005, p. 127).

When considering how agency emerges, Coole argues for breaking it down into a series of contingent phenomena and then reflecting on agentic propensities as a variety of processes at diverse levels of "(co)-existence" (Coole, 2005, p. 128). At one pole of an individual's interworld is what she calls "pre-personal, non-cognitive bodily processes" and at the other "transpersonal, intersubjective processes" (Coole, 2005, p. 128). Agentic properties emerge and interact across this whole agentic spectrum. Analysis therefore involves recognizing how all points on the agentic spectrum co-exist and interact. Relation, always a part of collective life, operates in pre-cognitive, somatic dimensions, requiring us to visualize how bodies act and suffer, how power is enacted, and how communication takes place through a mute yet eloquent corporal co-existence (Coole, 2005, p. 128). Hence, agentic properties or capacities emerge as inter-corporal experiences.

We are also inspired by what has come to be known as enactive theory, enactivism and enactive phenomenology. Involving a connection between phenomenology and the cognitive siences (the interdisciplinary study of mind, brain and behavior), this has been described as a "rebirth of phenomenology" (Gallagher, 2017; Stilwell & Harman, 2021).

This combination puts the insight of phenomenology to work on issues that have defined it from its beginning: consciousness, intentionality, perception, cognition, action, intersubjectivity, and so on. The rethinking implies rethinking both cognitive sciences and phenomenology (Gallagher, 2012).

Enactive approaches to understanding cognition emphasize the role of the body in cognition. Varela, Thompson and Rosch's book 'The Embodied Mind' (1992) is generally seen as the seminal text initiating the enactivist approach. In their introduction, the authors establish their closeness to phenomenology thus:

> "We like to consider our journey in this book as a modern continuation of a program of research founded over a generation ago by the French philosopher, Maurice Merleau-Ponty" (Varela, Thompson & Rosch, 1992, p. xv).

From an enactivist perspective, the perceptual system extends beyond the brain to include the organism (brain-body) embedded in or engaged with an environment that is characterized by certain regularities, affordances and action possibilities (Gallagher, 2012, p. 121). Affordance is about our perceiving the world as a set of affordances, or invitations to action. Thus, a chair affords sitting, a table affords writing, and a mountain invites us to ascend it or enjoy its majesty.

Another key concept in enactive-phenomenology is participatory sense-making: "an ongoing and dynamical process" of social understanding (Fuchs & De Jaegher, 2009, p. 465). The core argument here is that participants' sense-making acquires a coherence through their interactions, both in the physical form such interactions assume and also in their significance. Participatory sense-making is therefore the co-ordination of intentional activity in interaction, whereby individual sense-making processes are affected and new aspects of social sensemaking can be generated that are not available to an individual on their own (DeJaegeher & Paolo 2007, p. 497).

Methodology

Autoethnography seems to be a particularly relevant approach for our examination of our own experiences of doing research with children. Autobiographers often write about remembered moments perceived as having had a significant impact on their life, moments which in different ways have compelled them to attend to and analyse these lived experiences (Ellis et al., 2011; Holman Jones, 2016). In our case, we perceived our lived experiences arising from research with children as having had a significant impact on us as researchers. It was for this reason that we made these experiences the subject of analysis and discussion in this article. We find the autoethnographic approach, with its ability to fuse personal narratives with sociocultural exploration (Holman Jones, 2016), particularly fruitful.

Additionally, we applied an enactive phenomenologically approach, which we regard as a flexible resource for qualitative researchers examining the unfolding and meaning of first-person experiences (Stilwell & Harman, 2021). The persons who have such experiences (the researchers, in the case of our study) are those with an epistemic privilege to the experiences under examination. The construction of narratives based on the researchers' memos from the research process provides a first-person perspective. Of importance to enactive phenomenology is the perception of first-person (subjective) experience as both private and relational, since subjectivity is always inter-subjective (Gallagher, 2012; Merleau-Ponty, 1962/2002). This means that the researchers' experiences from the research encounters are created in the inter-world between the participant and the researcher. This is in line with participatory sense-making, a key concept in enactive-phenomenology.

On this basis, we sought to examine the unfolding of agency 'in-between' child and researcher in three specific situations. Based on the study's theoretical framework and the dynamic and context-sensitive nature of participatory sense-making, we have made use of the concept of 4E cognition (Newen et al., 2018). The 4 Es, a shorthand phrase attributed to Gallagher[1], represents a new way of thinking about cognition and the mind, rooted in both phenomenology and the cognitive sciences (Gallagher, 2017; Newen et al., 2018). Research based on it has been published in various domains, including mathematics education (see Reid, 1996); architecture (see Jelic et al., 2016); cerebral palsy (see Martiny, 2016); correctional/criminal rehabilitation (see Dent et al., 2020); autism (see De Jaegher, 2013); clinical reasoning in physiotherapy (see, Øberg et al., 2015); and the experiental dimension of lower back pain (see Stilwell & Harman 2021). It has also been discussed as a potential framework for a renewed phenomenological research approach (Stilwell & Harman, 2021). The 4 Es refer to the terms: Embodied; Embedded; Enactive: and Extended (Gallagher, 2017; Newen et al., 2018). Stilwell and Harman (2021) added another E: Emotive and renamed the approach as the '5E' process, since it involves five core elements. These five Es will form the framework for our analyses of the selected examples from the researchers' memos.

Brief description of the 5 Es

The term 'embodied', which plays a central role in phenomenology, refers to the notion that meaning-making is grounded in our corporality: we are the body that we have, and our body is the potential for a certain world (Merleau-Ponty, 1962/2002). It is on the basis of the bodies we are at any time in life that we understand and make sense of our self, others, things and the situations we are part of in our inter-corporal and inter-worldly being (Coole, 2005; Gallagher, 2012; Merleau-Ponty, 1962/2002).

'Embedded' refers to the way an individual is always situated in a specific situation or setting: the inter-world he or she inhabits. This implies that participatory sense-making is created in-between individuals situated in a common inter-world. As embodied, embedded individuals, we address the opportunities for action we perceive ourselves to have in every situation we are part of. On this basis we are 'enactive'; our participatory sense-making derives from our being the bodies we are in every situation, in tandem with our understanding of our possibilities for action in specific situations.

The fourth E, 'extended', refers to the way in which an individual's extended environment (including large-scale cultural, social, academic, and scientific institutions) forms part of every participatory sense-making process (Newen et al., 2018).

The final E 'emotive' refers to the way in which emotions evoked in different situations are always essential to our meaning-making. (Stilwell & Harman, 2021). We see this as in line with the term 'affectivity' (Colombetti, 2017). Central to this concept is the idea that interaction and sense-making are not simply about the processing of information by individuals; rather, interaction processes move individuals in their sense-making activities, and these include affect (De Jaegher, 2015, p. 124).

Data base

As already noted, the data used in this study involves extracts from the authors' memos regarding two qualitative studies involving children as participants.

The inclusion criteria of **the first study** stipulated children with physical disabilities. The participants were recruited from different health care services in municipalities located in southern Norway. In total, 15 children (aged 12–14 years) with physical disabilities were interviewed between one and four times during their transition from primary to secondary school. The author carried out a total of 26 interviews with children, 16 interviews with parents and six interviews with the children's school aides or teachers.

The **second study** had different inclusion crieteria. Participants were to be children who had *either* been diagnosed with serious congenital heart disorders (implying they had undergone a surgical procedure involving multiple and complex corrections during their first year of life) or had been diagnosed as having a motor function disability. All participants in the last group would have agreed to take part in a year-long innovative movement group, involving weekly sessions with other children. The participants were recruited from two different entities within Norway's specialist health services, one at the national level and the other at the county level.

The children participating in the movement group had been diagnosed with cerebral palsy, spina bifida/myelomeningocele or hereditary spastic paraplegia. The researcher interviewed all 23 participating children (age 4–12 years) and the parents of 21 of them. She also observed 14 of the children during 1 day at school; observed seven of the children at one of their weekly physiotherapy sessions; and carried out participatory observation with 12 of the children by participating in the year-long movement group (the weekly sessions were videotaped).

Findings

The three examples from the memos presented here were selected, written, and rewritten collaboratively by all three authors of this article.

The first extract (Example One) comes from a telephone conversation regarding participants' recruitment process. Examples Two and Three record specific moments during interviews with two children. In each case, the researcher's experience (as narrated in the extract) is immediately followed by a discussion in which the content is analysed and reflected on.

All participants' names are fictitious. When writing up the narrated examples we chose to use first person singular pronouns to make it clear that these examples are based on the researchers' experiential memos.

Example One

As part of the recruitment process for my research project, I sought to recruit Alex (a boy aged 12). The following extract is from notes I made following a telephone communication with Alex's mother:

> When she [Alex's mother] had first talked to Alex about the project, he had been eager to participate and to be interviewed by a researcher who wanted to talk to him about his opinions concerning his everyday life and in particular his school life. However, when reading the information letter together with his mother he had stopped at the following sentence: *we will interview children who have a physical disability.* He immediately stated: "but this is not me". His mother had tried to explain what physical disability mean, but Alex no longer wanted to be part of the project and refused to sign the consent form. Hearing this, I felt upset, disappointed and sad since I had really hoped he would participate in my project.

At the start Alex had been interested in sharing his experiences with a researcher. But he had changed his mind abruptly when reading through the information and consent letter. Even though Alex had a medical diagnosis that implied physical disabilities, he rejected being included in the category "children with disabilities". Perhaps he felt hurt by being categorized as a "child with a disability".

The above example illustrates what being disabled means to the individual child. Children may understand being described as disabled in different ways. The researcher had followed research ethics guidelines for the design of information and consent letters. In Norway, the guidelines stipulate that researchers must describe or define the target sample in

communications inviting individuals to participate in a specific project. This example made us aware that such guidelines may not be well adapted to children's understanding.

This raises an important question: how to describe why and how a child belongs to a strategic category in a way that is meaningful for them.

Also interesting here is the fact that it was Alex's mother who told him about the research project and who read the information and consent letter with him. What she actually said and how the dialog between them unfolded, we do not know. But Alex's immediate reaction to the phrase "children with disabilities" when he read it in the information and consent letter was clearly the trigger for him to change his mind about participating in the research project.

The way in which Alex's agency is revealed recalls observations by Shaun Gallagher (2012) regarding pre-reflective self-awareness as including a sense of agency (the experienced capacity to act). In the case of Alex, his agency in refusing to participate in the project may also be understood as rooted in his lived experience of being the body he is. He simply does not agree that his bodily being can be described as 'disabled'. His agentic capacity, rooted in being the body he is, seems significant for his expressed choice of action. His agentic capacity seems to be clearly embodied and embedded and nourished by the situation of reading and absorbing the formulation in the consent letter. In this encounter between Alex (with his self-understanding) and the socio-cultural understanding of children with disabilities set out in the text there seems to be little possibility of a common meaning-making process. As Alex reads the text, his self-understanding drives him to act, to stand up for himself by using his agentic capacity to refuse to participate in the project. This reveals how the narrative aspect of self is tightly interwoven with concepts of action and agency and that the constitution of individual selves takes place within social contexts (Gallagher, 2012, p. 132).

Writings are social and cultural bearers of meaning. In the meeting between reader and text, meaning-making can be understood to be created as a participatory sense-making process (De Jaegher, 2013). In this example, it is a process of sense-making about the meaning of disability. In the mother's telling, strong emotions form the basis for Alex's decision to refuse to participate, revealing how his agentic capacity is also rooted in emotions or affect.

The researcher's disappointment and sadness at Alex's decision not to participate is interesting. Disappointment and sadness can also be traced in Alex's behaviour. This mutual sadness and disappointment is created in-between the two parties, revealing how inter-affectivity is involved in the process of participatory sense-making (De Jaegher, 2015). The example also reveals that while Alex understands the situation and considers his needs and opportunities for action, the researcher is placed on the sidelines, without any opportunity to intervene or act as she herself was not interacting with Alex. Nevertheless, she acts by respecting Alex's choice not to participate, as conveyed via his mother.

Example Two

Peter (aged 13) has been diagnosed with both physical and cognitive impairments. The following excerpt is from the researcher's memo after her interview with Peter.

> When during the interview I asked Peter: 'What it is like to be disabled?', he hesitated a bit and in a low voice asked: 'Am I disabled?' Hearing his response and seeing his sadness I immediately regretted having asked the question. I was embarrassed and felt a great deal of discomfort at having put him in such an uncomfortable situation. Attempting to restore the previously good atmosphere and situation I tried to explain why I had asked this question. I told him it was because of his having a medical diagnosis, which often is related to having a disability. His father interrupted and tried to explain this to Peter, using different words. After a short while I said to Peter: 'Disability. It may not be a word you use?' 'No,' Peter immediately replied in a low voice. After a few seconds he added: 'I think those who are disabled, they are … a bit more …a bit worse than me.'

Like Alex, Peter seems not to perceive himself as fitting into the category of 'child with a disability'. Despite the efforts of both his father and the researcher to explain to him the meaning of the question asked, he does not see himself as disabled. For Peter, to be labelled 'disabled' you must be 'worse': you must have more problems around being active in everyday life than he perceives himself to have. This illuminates how categories of bodies are positioned and expressed within concrete situations, always mediated by a range of institutional and social factors. This insight is of importance for an understanding of how different bodies exhibit their agency (Coole, 2007), and it also underlines the need to pay attention to the way interacting bodies communicate within social encounters (such as a research interview).

Peter's enacted agency, both embodied and embedded, appears and is expressed in a different way than in the example with Alex. In this case we get Peter's own explanation as to why he does not perceive that the label 'disabled' is appropriate for him. It could be that the researcher makes it possible for him to articulate his point of view by asking him whether 'disability' might not be a word he uses. According to Peter's reasoning, a certain number of problems or difficulties are required for a child or person to be said to be disabled.

When Peter quietly but firmly uses his agency to ask the counter-question "am I…?", the researcher perceives him as sad at being categorized as disabled. In the moment, the researcher feels embarrassed for having asked this question. However, by posing the question "how is it to be disabled?" she offers Peter an opening to elaborate on his understanding of the concept. He seizes this offer. The agency of researcher and child emerge in the dialogue, in the space in-between them (the intersubjective field or 'interworld' (Coole, 2005, p. 139) and in the process of participatory sense-making. Asking Peter whether the word 'disability 'was not one he was accustomed

to using gave him the chance to elaborate. By this means, the researcher gained insight into Peter's understanding of the term "disability", which in other circumstances might have remained unspoken and unknown.

Peters' sadness when being 'othered' by the researcher as disabled is interesting. He himself subsequently others 'children who are worse' – for him the truly disabled – thereby revealing the particular bodily and socio-cultural meanings he ascribes to disability.

Despite having diagnoses that from a medical perspective imply disability, both Alex and Peter seem to see themselves, first and foremost, as children – as being the bodies they are.

Example Three

This example describes something that took place during the interview with Gustav, who is 7 years old and has a medical diagnosis of cerebral palsy (CP):

> Gustav takes me into the living room and closes the door. "My little sister can't disturb us now," he explains. We sit down on the sofa next to each other. Shortly after the interview starts, I tell him that I know he's been diagnosed with cerebral palsy (CP), but that I don't know what it's like for him to have this condition. What's it like for him when he moves, plays and is active at school? What's it like during his leisure time with family and friends? "This is what I'd very much like you to tell me about", I add. Gustav begins to move. He rocks and twists his body and slowly moves down from the sofa to lie on the floor beneath the coffee table right in front of my feet. I feel both his and my own discomfort. After a short time I change the topic. "What do you like to do at school?" I ask. Still lying on the floor, Gustav begins to recite a nursery rhyme. Impressed, I lean forward, look him in the face and declare: "Wow; so great you have learned this whole verse … wow, it's good". Not long after, Gustav starts climbing back onto the sofa again. Once again seated next to me, he with a clear and distinct voice recites the rhyme once more. Once again, I express how impressed I am. Gustav straightens up a little on the sofa, and in a low voice says; "I can read, so really ... I do not have CP."

Again, the researcher is confronted with the child's understanding of a medical diagnosis, and his perception of not belonging to the category this diagnosis indicates. By explaining that since he can read he cannot have CP, Gustav reveals an understanding of what having CP means and implies to him. This understanding does not coincide with a health professional's understanding of the diagnosis. At the same time, not being able to read is something which is a reality for some children with this particular diagnosis.

Gustav relates an understanding of CP associated with bodily style, capacity, specifically cognitive capacity and skill, and on that basis rejects the idea that the CP category applies to him. The heterogeneity of the diagnosis and the different ways in which it may manifest to specific individuals appears to pose a challenge for children who are diagnosed with CP. In addition, the researcher finds her use of categories under challenge. She assumes she is using a category to which Gustav perceives himself to belong.

The unfolding dialogue between researcher and child clarifies how different bodily beings and experiences enable different forms of embodied agency. In the dialogue, the use of normative categories and understandings seems to be perceived by the child as stigmatizing, marginalizing, and excluding. This experienced exclusion, albeit at a pre-reflective level, seems to trigger Gustav's agentic power to contradict, to articulate an understanding of the diagnosis which goes against the normative professional researchers' explanations and understandings. The ways in which different bodies – different embodiments – affect communication is especially important for understanding normative phenomena such as exclusion and felt exclusion (Coole, 2007, p. 413).

In all three extracts, the children resist being labelled and excluded, exhibiting a defiance we believe needs to be taken seriously. The same applies to the researcher's feeling of embarrassment and shame for having labelled the children during the course of research.

In the discussion we will elaborate on the methodological issues this may raise for qualitative research with children, understood as processes of participatory sense-making. We will further discuss agency and inter-affectivity in-between the children and the researchers as embodied situated and affective body-subjects as illuminated in our findings.

Discussion and Concluding Remarks

What are the implications of our findings for qualitative research with children? In the first place, they demonstrate how children and researchers enact agentic capacity or properties across a broad agentic spectrum, from "pre-personal, non-cognitive bodily processes" to "transpersonal, intersubjective processes" (Coole, 2005, p. 128). By applying the 5 Es approach as an analytical strategy (Stilwell & Harman, 2021) our findings illuminate how agentic capacity, understood as embodied, embedded, enacted, extended and emotive, shifts and assumes a variety of expressions within this agentic spectrum.

In addition, the findings show how the process of implementing and performing qualitative research implies a process of participatory sense-making, where interaction includes bodily resonance. This underlines the multi-level character of agentic capacity and the way it provides the basis for understanding our own and each other's gestures and vocal expressions (Fuchs & De Jaegher, 2009). In qualitative research (understood as a process of participatory sense-making), interaction and meaning-making in-between child and researcher is dependent on the researcher's vigilance towards the individual child's behaviour and on the researcher's ability to provide an inter-subjective space (an interworld) where the child can take the opportunity (or not) to express their opinions, ask their questions and elaborate on what they think and feel. If qualitative research is seen as a

process of participatory sense-making, interaction and co-existence is understood to modulate the participants (child, researcher) and thereby partly make them who they are at given moments during the process (De Jaegher, 2013).

In such processes, specific categories of bodies, by being the bodies they are, will always be positioned and expressed within the specific socio-cultural situation they at any time inhabit and are part of (Coole, 2007; Merleau-Ponty, 1962/2002). When research involves pre-defining and pre-describing specific categories of bodies, this carries implications for the individuals whose bodies are thus described. Individual bodies find themselves being assigned specific discursive properties, possibilities, and capacities for acting and living their lives. Being characterised in such ways interacts with the individual's self-perception as well as with their lived experience of how they are perceived by others. It is therefore of importance for the participatory sense-making between the two parties in the encounter and for participants' communication and interaction during, as in our case, the research process.

A process which takes place as mutual incorporation, where the lived bodies of the participants extend into common intercorporality and generation of common meaning (Fuchs & De Jaegher, 2009), may sometimes result in contradictory or untuned meaning-creation. Since situated (embedded) and embodied social agents who act and think (enact) always try to get the best grasp of what is happening in the situations they inhabit (Gallagher, 2012), children and researchers, as self-organizing, self-maintaining, embodied agents, meaningfully connect with and take part in each other's meaning-making (De Jaegher, 2013, p. 1). But this does not always lead to agreement and coherence; it can also reveal different, even contradictory views, opinions, and understandings. Since adults, by virtue of their adult status, are generally understood to possess greater authority and power than children in their interactions, it is vital that in qualitative research children get the opportunity not only to have a say but also to have their contribution recognized and seen as significant.

Coole's (2005) understanding of agency as intrinsically embodied implies recognition of the corporality of thinkers and their situatedness (embeddedness). This has significant implications for the methodology used to detect and participate in its mode of appearing (Coole, 2005, p. 127). It also implies recognition of inter-affection and meaningful engagement as part of agency, along with the central importance of being seen and understood (De Jaegher, 2015).

In the case of children, the power to marginalise them by labelling them 'children with CP', 'children with a disability' or 'disabled children' may cause their agentic power to take counteractive measures. The children may reject being thus marginalised, stigmatized or 'othered'.

When adults, researchers, and parents avoid explaining the meaning of concepts to children, children may repudiate the categories they are said to belong to. Here they can be understood to enact agentic power on account of their lack of competence and their poor understanding of a concept such as disability. However, the children also exercise counter-power by protesting against the marginalization they feel exposed to. This in turn can contribute to a shift in the power balance where the children's reactions contribute to the researchers feeling ashamed and embarrassed about their own action or choice of words. This illuminates Coole's (2007) argument (with reference to Foucault) that power circulates in the capillaries of society through technics and strategies that are too trivial or banal, anonymous, and invisible to be immediately recognized as an exercise of power.

While from the point of view of an adult or a medical professional a child's understanding of concepts such as 'disability' and CP may be deficient, this study reveals the embodied, embedded and emotive experience children possess in relation to such concepts. They may use their own knowledge, based on their lived experiences, to oppose being labelled, marginalized or excluded. By this means they demonstrate their agency, using it as an extended force able to oppose certain forms of cultural, social, academic, and scientific knowledge.

In the case of the children in the current study, their knowledge-based agency is directed against the current prevailing orthodoxy regarding what types of body (including children's bodies) lie within or outside the norms of society and the health care system. This opposition can be seen as a powerful expression of the view that children, just like adults, constitute a broad and diverse category in which there must be room for variation. It speaks to an agentic force that qualitative researchers cannot afford to overlook if children's voices are to be heard and their agency respected as a significant source of knowledge. That said, our findings show that their voices and agency are created in the interaction between them and the researchers – meaning that children's voices and agency must be understood as inter-subjective voices and agencies created in interpersonal interactions. This harmonizes with Coole's use of the term 'singularity' to denote individual and collective agents whose uniqueness as virtual forms and potential compositions is always in the making; this uniqueness (singularity) derives from a particular way of weaving together the perceptual and cultural fields (Coole, 2005, p. 133).

It is through lived and practical relations in the world with others that individual and collective singularities appear, are nourished, and are developed (Coole, 2005, p. 134). This is in line with an understanding of agency from an interconnected and relational perspective, where it has been argued that children's agency can only be brought about in relation and interconnectedness (Raithelhuber, 2016). Of relevance here is the notion that selfhood is neither fixed nor essential, for we exist in dynamic relationship with our social world (Krause, 2011, p. 301). Enactive theory, and in particular enactive phenomenology, propose that we can literally participate in each other's sense-making and, by implication, can affect the ongoing processes that give rise to our autonomy (De Jaegher 2015, p. 127).

The main point of children's participation in qualitative research is said to be that such participation ensures that children are *involved* in the project (Kellett, 2010; 2011). If children are to be involved, and to *experience* being involved, the relationship between children and researchers has to be open, shared and based on trust. It needs to be one where researchers support children, give them the opportunity to express their opinions and knowledge, and help them make their own decisions (Ericsson & Boyd, 2017; Oulton et al., 2016).

In the examples discussed in this article, the researcher's felt and observed discomfort reveals how qualitative research, understood as a process of participatory sense-making, involves an embodied, embedded, emotive, enacted, and extended process of agentic power, one in which there is pushing and being pushed, moving and being moved.

To experience their involvement in qualitative research as a participatory sense-making process, children must not only have the right to express their experiences, views, and opinions. They must also have their utterances, no matter how challenging, confusing, surprising, or uncomfortable these may be for the researcher, taken seriously. Rather than being ignored or put into storage, children's contributions should be highlighted as potential additions to methodological knowledge in qualitative research. In the interworld of qualitative research, the coexistence of child and researcher is all about being exposed to one another's views, experiences, and opinions (Nancy, 2000, p. 187).

How meaning-making is created and developed in such processes is of great interest to those conducting qualitative research. Sharing and being involved in qualitative research is about people *being with* each other. Elaborating on *being with*, Nancy (2000, p. 35) argues that:

> 'With' does not indicate the sharing of a common situation any more than the juxtaposition of pure exteriorities does (for example, a bench with a tree with a dog with a passer-by).

In this sense, sharing and being involved in a common situation demands more than merely being in the same place at the same time. For Nancy (2000, 2008), this is a situation which also calls for 'dis-placement', for genuine openness to what might be put into play between child and researcher. In particular, it is about the willingness of researchers to 'dis-place' themselves by moving towards the child with interest and respect, ready to share, listen – and learn. On the basis of our study, with its enactive and phenomenological perspective, we emphasize the need to explore the agency of all those involved in qualitative research, including participants whose youth and unfamiliarity with adult discourse can lead us to undervalue their agentic potential and profound knowledge of their own reality.

Acknowledgments

Declaration of Conflicting Interests

Funding

ORCID iD

Wenche Schrøder Bjorbækmo https://orcid.org/0000-0002-0494-096X

Note

1. "The origin of the '4E' label has been attributed to me (see Rowlands, 2010, p. 3). I accept only partial credit (or blame). In 2007 I organized a conference on 4E cognition at the University of Central Florida, and used that term. But the label itself emerged from a workshop on the Embodied Mind at Cardiff University, in July 2006, which included the following participants: myself, Richard Gray, Kathleen Lennon, Richard Menary, Søren Overgaard, Matthew Ratcliffe, Mark Rowlands, and Alessandra Tanesini" (Gallagher, 2017, p. 51).

References

Asbjørnslett, M. (2015). *Ordinary kids": Everyday life experiences of children with disabillities. Dissertaion*. The Norwegian Scholl of Sport Sciences.

Bjorbækmo, W. S. (2011). *My own way of moving: The movement experiences of children with disabilities*. Dissertation, University of Oslo.

Bourke, R. (2017). The ethics of including and 'standing up' for children and young people in educational research. *International Journal of Inclusive Education*, *21*(3), 231–233. https://doi.org/10.1080/13603116.2016.1260823

Christensen, P., & James, A. (2008). Researching children and childhood cultures of communication. In P. Christensen, & A. James (Eds.), *Research with children* (pp. 1–9). Routledge.

Collier, D. R. (2019). Re-Imagining research partnerships: Thinking through "Co-research" and ethical practice with children and youth. *Studies in Social Justice*, *13*(1), 40–58. https://doi.org/10.26522/ssj.v13i1.1926

Colombetti, G. (2017). Enactive affectivity, extended. *Topoi*, *36*(3), 445–455. https://doi.org/10.1007/s11245-015-9335-2

Coole, D. (2005). Rethinking agency: A phenomenological approach to embodiment and agentic capacities. *Political Studies*, *53*(1), 124–142. https://doi.org/10.1111/j.1467-9248.2005.00520.x

Coole, D. (2007). Experiencing discourse: Corporeal communicators and the embodiment of power. *The British Journal of Politics and International Relations*, 9(3), 413–433. https://doi.org/10.1111/j.1467-856x.2006.00258.x

Daelman, S., De Schauwer, E., & Van Hove, G. (2020). Becoming-with research participants: Possibilities in qualitative research with children. *Childhood*, 27(4), 483–497. https://doi.org/10.1177/0907568220927767

De Jaegher, H. (2013). Embodiment and sense-making in autism. *Front Integr Neurosci*, 7, 15. https://doi.org/10.3389/fnint.2013.00015

De Jaegher, H. (2015). How we affect each other. Michel Henry`s 'Pathos-With' and the enactive approach to intersubjectivity. *Journal of Consciousness Studies*, 22(1-2), 112–132.

De Jaegher, H., & Di Paolo, E. (2007). Participatory sense-making. *Phenomenology and the Cognitive Sciences*, 6(4), 485–507. https://doi.org/10.1007/s11097-007-9076-9

Dent, H., Nielsen, K., & Ward, T. (2020). Correctional rehabilitation and human functioning: An embodied, embedded, and enactive approach. *Aggression and Violent Behavior*, 51, 101383. https://doi.org/10.1016/j.avb.2020.101383

Ellis, C., Adams, T. E., & Bochner, P. (2011). Autoethnography: An overview. *Historical Social Research (Koln)*, 36(4), 273–290. http://www.jstor.org/stable/23032294

Ericsson, S., & Boyd, S. (2017). Children's ongoing and relational negotiation of informed assent in child–researcher, child–child and child–parent interaction. *Childhood (Copenhagen, Denmark)*, 24(3), 300–315. https://doi.org/10.1177/0907568216688246

Facca, D., Gladstone, B., & Teachman, G. (2020). Working the limits of "giving voice" to children: A critical conceptual review. *International Journal of Qualitative Methods*, 19, 160940692093339. https://doi.org/10.1177/1609406920933391

Fuchs, T., & De Jaegher, H. (2009). Enactive intersubjectivity: Participatory sense-making and mutual incorporation. *Phenomenology and the Cognitive Sciences*, 8(4), 465–486. https://doi.org/10.1007/s11097-009-9136-4

Gallagher, M. (2008). Foucault, power and participation. *The International Journal of Children's Rights*, 16(3), 395–406. https://doi.org/10.1163/157181808X311222

Gallagher, M., Haywood, S. L., Jones, M. W., & Milne, S. (2010). Negotiating informed consent with children in school-based research: A critical review. *Children & Society*, 24(6), 471–482. https://doi.org/10.1111/j.1099-0860.2009.00240.x

Gallagher, S. (2012). *Phenomenology*. Palgrave MacMillan.

Gallagher, S. (2017). *Enactivist interventions: Rethinking the mind*. Oxford University Press.

Graham, A., & Fitzgerald, R. (2010). Children's participation in research: Some possibilities and constraints in the current Australian research environment. *Journal of Sociology (Melbourne, Vic.)*, 46(2), 133–147. https://doi.org/10.1177/1440783309355065

Greene, S., & Hill, M. (2006). Researching Children`s experience: Methods and methodological isssues. In S. Greene, & D. Hogan (Eds.), *Researching children`s experience. Approaches and Methods* (pp. 1–22). SAGE Publications.

Grindheim, L. J., Borgen, J. S., & Ødegaard, E. E. (2020). In the best interests of the child: From the century of the child to the century of sustainability. In E. E. Ødegaard, & J. S. Borgen (Eds.), *Childhood cultures in transformation, 30 Years of the UN convention on the rights of the child in action towards sustainability* (pp. 13–36). Brill Sense.

Harcourt, D., & Sargeant, J. (2011). The challenges of conducting ethical research with children. *Education enquiry*, 2(3), 421-436. https://doi.org/10.3402/edui.v2i3.21992

Hill, M. (2006). Ethical considerations in researching children`s experiences. In S. Greene, & D. Hogan (Eds.), *Researching children`s experience* (pp. 61–87). Sage Publications.

Holman Jones, S. (2016). Living bodies of thought: The "critical" in critical autoethnography. *Qualitative Inquiry*, 22(4), 228–237. https://doi.org/10.1177/1077800415622509

Jackson, A. Y., & Mazzei, L. A. (2009). *Voice in qualitative inquiry*. Routledge.

James, A., Jenks, C., & Prout, A. (2012). *Theorizing childhood*. Polity Press.

Jelic, A., Tieri, G., De Matteis, F., Babiloni, F., & Vecchiato, G. (2016). The enactive approach to architectural experience: A neurophysiological perspective on embodiment, motivation, and affordances. *Frontiers in Psychology*, 7(MAR), 1–20. https://doi.org/10.3389/fpsyg.2016.00481

Kellett, M. (2010). Small shoes, big steps! Empowering children as active researchers. *Am J Community Psychol*, 46(1), 195–203. https://doi.org/10.1007/s10464-010-9324-y

Kellett, M. (2011). Empowering children and young people as researchers: Overcoming barriers and building capacity. *Child indicators research*, 4(2), 205–219. https://doi.org/10.1007/s12187-010-9103-1

Kjørholt, A. T., & Winger, N. (2013). Barndom og rettigheter under lupen. Individualisering, verdighet og menneskeverd. In A. Greve, S. Mørreaunet, & N. Winger (Eds.), *Ytringer om likeverd, demokrati og relasjonsbygging i barnehagen* (pp. 75–89). Fagbokforlaget.

Krause, S. R. (2011). Bodies in action: Corporeal agency and democratic politics. *Political Theory*, 39(3), 299–324. https://doi.org/10.1177/0090591711400025

Martiny, K. (2016). Embodying investigations of cerebral palsy: A case of open cognitive science (Issue June 2015) [Københavns Universitet]. https://doi.org/10.13140/RG.2.1.1193.7529

Merleau-Ponty, M. (1962/2002). *Phenomenology of perception*. Routledge.

Montreuil, M., Bogossian, A., Laberge-Perrault, E., & Racine, E. (2021). A review of approaches, strategies and ethical considerations in participatory research with children. *International Journal of Qualitative Methods*, 20, 160940692098796. https://doi.org/10.1177/1609406920987962

Montreuil, M., & Carnevale, F. A. (2018). Participatory hermeneutic ethnography: A methodological framework for health ethics research with children. *Qualitative Health Research*, 28(7), 1135–1144. https://doi.org/10.1177/1049732318757489

Nancy, J.-L. (2000). *Being singular plural*. Stanford University Press.

Nancy, J.-L. (2008). Corpus.

Newen, A., De Bruin, L., & Gallagher, S. (2018). *The Oxford handbook of 4E cognition*. Oxford University Press.

Øberg, G. K., Normann, B., & Gallagher, S. (2015). Embodiedenactive clinical reasoning in physical therapy. *Physiotherapy Theory and Practice*, *31*(4), 244–252. https://doi.org/10.3109/09593985.2014.1002873

Öneren Şendil, Ç., & Sönmez, S. (2020). Ethics in research including young children: Views and experiences of researchers. *Ilköğretim Online*, *19*(1), 87–99. https://doi.org/10.17051/ilkonline.2020.644821

Oswell, D. (2013). *The agency of children*. Cambridge University Press.

Oulton, K., Gibson, F., Sell, D., Williams, A., Pratt, L., & Wray, J. (2016). Assent for children's participation in research: Why it matters and making it meaningful: Assent for children's participation in research. *Child : care, health & development*, *42*(4), 588–597. https://doi.org/10.1111/cch.12344

Raithelhuber, E. (2016). Extending agency, the merit of relational approaches for Childhood Studies. In F. Esser, T. Betz, & B. Hungerland (Eds.), *Reconceptualising agency and childhood : New perspectives in childhood studies* (pp. 1–13). Routledge.

Reid, D. A. (1996). January). Enactivism as a methodology. *Proceedings of the Twentieth Annual Conference of the International Group for the Psychology of Mathematics Education, (Vol. 4.,*, 203–210.

Rowlands, M. (2010). *The New Science of the Mind*. Cambridge, MA: MIT Press.

Stilwell, P., & Harman, K. (2021). Phenomenological research needs to be renewed: Time to integrate enactivism as a flexible resource. *International Journal of Qualitative Methods*, *20*, 1609406921995299. https://doi.org/10.1177/1609406921995299

Tisdall, E. K. M., & Punch, S. (2012). Not so 'new'? Looking critically at childhood studies. *Children's Geographies*, *10*(3), 249–264. https://doi.org/10.1080/14733285.2012.693376. Convention on the Rights of the Child (1989).

Unicef. (1989). Convention on the Rights of the Child.

Varela, F. J., Rosch, E., & Thompson, E. (1992). *The embodied mind: Cognitive science and human experience*. MIT Press.