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Working together as scientific and experiential experts: how do current ethical PAR-principles work in a research team with young adults with Developmental Language Disorder?

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ABSTRACT

Participatory Action Research (PAR) brings unique ethical challenges. Scholars have developed seven ethical principles to address these challenges. So far, little has been published on how these ethical principles (are put to) work in different fields. We used the principles to evaluate our collaboration with co-researchers with developmental language disorder (DLD). This article aims to explore how the principles helped to reflect on the ongoing research practice. First, we needed to simplify the language of the principles so that the co-researchers could understand how they relate to concrete practices. Second, the co-researchers needed to be reminded of specific events before they could relate the principles to their own experiences. Lastly, for an evaluation of (co-) researchers dealing with multiple roles, from friend to colleague and client, this theme has been specifically included to the principle of personal integrity, so that it cannot be overlooked. Looking through a care ethical lens, we suggest speaking of *practical insights* rather than (ethical) principles, as it more clearly communicates that these insights are based on learning by doing and are not fixed, but build on (good) practices, whilst still allowing enough room for adjustments to the particularities inherent to each research process.

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Introduction

Participatory action research (PAR) is rapidly growing in popularity worldwide. This popularity is both bottom-up (*nothing about us without us*) and top-down: funders, policy-makers and research organizations increasingly expect a participatory approach for more effectiveness, credibility, and efficiency (Boylan, 2019). Action researchers aim to understand as well as improve practices with the people it concerns (Greenwood and Levin 1998; Reason and Bradbury 2008; Bradbury 2015). Instead of studying people as subjects to establish ‘the truth’, the participatory researcher respectfully steps into their lives and perceives reality as ‘the way in which the people involved with facts perceive them’ (Freire 1982; ICPHR, 2013). The researcher facilitates a mutual learning process through

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exchanging and changing perspectives with the participants, and together with participants bring about change by acting upon perceived needs and individual competencies (Orne and Bell 2015; Gibbs et al. 2018; Deding et al. 2022).

This PAR-process – often messy, unpredictable and emergent – raises various unique ethical issues (Banks and Brydon-Miller 2019, xx). For example, conflicts on who represents a group or community and who takes credits for findings (see Table 1 for an elaboration). Common ethical guidelines, such as the Declaration of Helsinki (World Medical Association, 1964, 2013) and the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979), do not cover these specific ethical issues. Moreover, they have been criticized by PAR researchers for creating a top-down approach of power and expertise, including a clearly defined distinction between the researcher and researched. This does not fit well in the idea of mutual learning and exchanging and changing perspectives in PAR, where the boundaries between researchers and researched can be blurred (Abma et al. 2019; Banks and Brydon-Miller 2019).

Since the common ethical guidelines were difficult to use in PAR-practices, Banks et al. (2013) decided to develop an alternative bottom-up ethical framework for more profound critical reflection of the realities and values of participatory research. Their framework is intended to enhance the awareness and understanding of the complexity of participatory research, the ability to tackle ethical challenges, and to encourage funders, academic and other institutions to modify some of their existing values, requirements and ways of

Table 1. The six main ethical issues in participatory research, followed by the seven ethical principles as defined by Banks et al. (2013) and summarized by Banks et al. (2019).

<i>The six ethical issues</i>	
1 Partnership, collaboration, and power	Tackling mismatches between timelines and expectations
2 Blurring the boundaries between researcher and researched, academic and activist	Tensions may arise for people who find themselves in roles of both researcher and community advocate, or academic and activist
3 Community Rights, conflict, and democratic representation	Conflict within and between communities and groups, deciding who represents group or community interest
4 Ownership and dissemination of data, findings and publications	Conflicts of interest regarding who takes credit for findings and what channels are used for dissemination
5 Anonymity, privacy, and confidentiality	Some participants may wish to be named and credited, others may not
6 Institutional ethical review processes	The difficulty of fitting PR into the process and procedures for institutional ethical review
<i>The seven ethical principles</i>	
1 Mutual respect	Developing research relationships based on mutual respect
2 Equality and inclusion	Encouraging and enabling people from a range of backgrounds and identities (e.g. ethnicity, faith, class, education, gender, sexual orientation, (dis)ability, age) to lead, design and take part in the research
3 Democratic participation	Encouraging and enabling all participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need
4 Active learning	Viewing research collaboration and the process of research as an opportunity to learn from each other
5 Making a difference	Promoting research that creates positive changes for communities of place, interest or identity
6 Collective action	Individuals and groups working together to achieve change
7 Personal integrity	Participants behaving reliably, honestly and in a trustworthy fashion

working (Banks et al. 2013; International Collaboration for Participatory Health Research (ICPHR) 2013). This framework includes a list of six ethical issues and a list of seven ethical principles. The latter has been adopted by the International Collaboration for Participatory Health Research (ICPHR): (1) mutual respect, (2) equality and inclusion, (3) democratic participation, (4) active learning, (5) making a difference, (6) collective action and (7) personal integrity (see Table 1).

Ethical practices, Banks & Brydon-Miller suggested, require researchers with ‘cultivated skills’ based on ‘the nuances of the particular situations and people’ in their research project (2019, 8). They recommend research partners to choose for ‘an agreed set of ethical principles’ (International Collaboration for Participatory Health Research (ICPHR) 2013, 12) and to pay particular attention to the form, content and communication of the agreement when the research partners include children or people with learning disabilities or cognitive impairments (Banks et al. 2013; International Collaboration for Participatory Health Research (ICPHR) 2013; Banks and Brydon-Miller 2019). So far, the principles have been used in practice, but reflections on its use and possible needed adaptations for certain groups and practices are rare.

To date, there are three known studies. The first, by Dedding et al. (2020), concerns an evaluation-based study on the seven principles to reflect on the process and its outcomes in the field of digital inclusion. They did not fully achieve the principles of *democratic participation* and *collective action* with citizens. Instead, they choose to mainly work with policymakers in order to accomplish quick results and short-term policy impact. They encountered the need for situated choices. The second study, by Groot et al. (2018), concerned an analysis with co-researchers of their participatory research in the field of acute psychiatric care. They noted that the seven principles did not tackle *the mutual responsibility of creating a safe setting*, in their case the responsibility of both scientific researchers and co-researchers with lived experiences in acute psychiatric care. They therefore suggested that in addition to these principles, Tronto’s (1993) care ethical insights might be useful in gaining a better understanding of the ethical challenges when working with co-researchers. In the third study, Stapleton and Mayock (2022) mention the use of the seven principles in combination with the Structural Ethical Reflection model, but they do not reflect on the use of these principles. They mainly focused on the power dynamics in their reflection.

In this article we reflect on the use of the ICPHR principles with co-researchers with developmental language disorder (DLD). DLD is a disorder affecting approximately 5–10% of young children (Tomblin et al. 1997; Law et al., 2000). The disorder occurs in childhood and is characterized by difficulties in learning and using language, both in communication with others and with oneself (inner language). DLD does not define one’s non-verbal intelligence, both people with low non-verbal intelligence and people with normal non-verbal intelligence can have DLD (Vissers et al. 2021). A person with DLD needs to work harder to listen to a simple sentence, process it, come up with a good answer and to put the answer into words. This also challenges their socio-emotional development, as they need extra time, attention, and energy to understand themselves, others, and the world around them. This can lead to problems such as a lack of confidence, extreme shyness, depression, anxiety, and strong emotional outbursts as well as long-term difficulties in people’s lives such as challenges regarding independent living and building and keeping social relations (Conti-Ramsden et al., 2017; Isarin 2012, Isarin 2021; Vissers et al. 2021).

The outcomes of the project, entitled *TOSKoploper* (DLD Fronrunner), will be described elsewhere (Aussems et al., forthcoming). The main aim of this article is to explore how the principles as described above actually help researchers and co-researchers to reflect on their ongoing research practice, and in particular co-researchers with DLD.

Case description

The Dutch project *TOSKoploper* aims to create space for young adults with DLD to reflect on their ways to independency, to share their experiences, to call attention to the issues most important to them and to get their voices heard by the people in their day-to-day lives, including professionals such as policymakers of city councils. A team of three co-researchers with DLD (Jérôme, Maartje and Meike) and three scientific researchers (Iris, Jet and Karijn) used an iterative learning process of data collection, analysis and reflection. As the research project started in the context of covid-restrictions (January 2020), this process was mainly done online.

The research team firstly invited respondents with the help of experiential experts and professionals in care and education. The inclusion criteria were for the respondent to have DLD, and to be a young adult (without fixed age bracket) and willing to take part in the research. Soon thereafter, the team created a group on Facebook and WhatsApp for the respondents and asked them to invite friends and relations with DLD. The researchers asked the respondents ($n = 26$) to share experiences of being home during lockdown, and to post drawings, pictures, poems, or any other forms of expression. At the same time, the researchers began inviting young people with DLD for online interviews, using Zoom as a medium. They interviewed the respondents ($n = 15$) in pairs of one co-researcher and one scientific researcher. The co-researchers preferred to interview respondents they were least familiar with, so that they would get to know new insights.

To encourage the respondents to speak freely, the researchers informed them *all* that matters is their personal experience and how they think that others can be responsive to their needs. The aim of this was to instill confidence and motivation amongst respondents to freely share what came to their minds. The research team developed a 'safety web', a model depicting the ways to ensure an ethical approach, to use for the interviews (this will be published in a separate forthcoming paper).

The researchers collectively analyzed the data during weekly Zoom-sessions (October 2020 – April 2021) using Microsoft Word comments as well as marking the text with colors. Transcripts were anonymized to avoid easy recognition. After each Zoom session, the co-researchers took the lead in writing a reflection of the sessions and personally shared this on WhatsApp, Facebook, and LinkedIn. Each main theme has its own written report, and six themes also have a short animation, e.g. one about abuse and how to set boundaries. Along the way these were posted on the website of *TOSKoploper* (www.deelkracht.nl/toskoploper). During the analysis, the research team took first steps to approach policy makers and professionals in the social domain of three cities, to invite them to work together to improve (1) access to information, (2) access to social support, and (3) responsiveness of professionals to the needs of people with DLD.

Methods

To explore how the seven ethical principles for PHR (Banks et al. 2013; Banks and Brydon-Miller 2019; International Collaboration for Participatory Health Research (ICPHR) 2013) help the researchers and co-researchers of *TOSKoploper* to reflect on their ongoing research practice, we held regular evaluation sessions with the research team throughout the research project. Halfway through the project (June 2021) the ethical PAR-principles were introduced, translated into Dutch (by Karijn), and converted to more understandable text (by Karijn and Meike) for the co-researchers. For example, one of the co-researchers did not understand 'social justice' (*sociale rechtvaardigheid*), and therefore it was changed into 'a just world' (*een eerlijke wereld*). Shorter sentences were preferred, such as 'everyone being prepared to listen to the voices of others' was shortened to 'everyone listens to the voice of others.'

Each team member was asked to individually take a look at the principles and to evaluate how the research team fulfils these principles, and to define whether these principles are important, or whether they thought something else is also or even more important (July 2021). Thereafter, the research team held an evaluation session of three hours on Zoom (Sept 2021). Three couples of one co-researcher and one scientific researcher took time to reflect on the seven ethical principles by using Jamboard, in which each couple noted their reflections. Thereafter, the team discussed this collectively. Each team member gave approval for the recording and wished to be named by their actual names.

After the research team had evaluated their ongoing research process, scientific researcher Karijn analyzed this evaluation with the support of team member Jet and critical friends (cf. Kember et al. 1997) Christine (PAR expert) and Alistair (care ethicist) and jointly formulated the lessons learned. This was done during four Zoom sessions of one hour and one-on-one dialogues between Karijn and Jet, Alistair and Christine (September – February 2021). The co-researchers remained involved by being updated and invited to give their responses, while they also wrote their own reflections that they shared on social media. See [Figure 1](#) for an overview of the teams, the roles of its members and each step that was taken during the iterative process.

Results

The first reaction of the co-researchers when looking at the simplified language of the ethical principles mainly led to somewhat generic answers. The co-researchers talked in terms of the *overall* group process in general. The co-researchers mainly noted that they enjoyed being in the team, and that they appreciated their role and influence, as they hadn't experienced it like this before. Co-researcher Meike wrote:

With many projects you mainly talk about the target group, but you still missed talking with the target group. Let alone working together. Fortunately, that is now being done more. And then there is also a difference in whether you ask someone with DLD a few times or if you really continue to work with them. We do the latter with our project. . . . And I think that's the most beautiful perspective.

TOSKoploper	Evaluation of teamwork	Evaluation of ethical principles
A participatory study with young adults with DLD on their way to independency	An evaluation of how we worked together as research team	An evaluation of how the ethical principles helped to reflect on the ongoing research practice
Team: 3 scientific researchers (Iris, Jet & Karijn) 3 co-researchers with DLD (Meike, Maartje & Jérôme) 26 respondents with DLD (incl. co-researchers)	Team: 3 scientific researchers (Iris, Jet & Karijn) 3 co-researchers with DLD (Meike, Maartje & Jérôme)	Team: 2 scientific researchers (Jet & Karijn) 3 co-researchers with DLD (Meike, Maartje & Jérôme) to validate the findings 2 critical friends (Christine & Alistair)

Figure 1. An overview of the teams, the roles of its members and each step that was taken during the iterative process.

When receiving these positive and general evaluations, scientific researcher Karijn wondered if the co-researchers felt free to refer to specific challenging situations. She recalled moments when the co-researchers expressed disagreement and frustration, as when the analysis of the interviews took longer than they had wished for and preferred quicker action. When Karijn brought in both positive and negative issues that she remembered, the co-researchers fully agreed with her analysis with the help of their own remarks, which ultimately led to a more nuanced evaluation. Table 2 provides an overview of how the principles were interpreted by the team, here formulated as *practical insights* (with concrete aims and actions), with an awareness that the covered practical insights are not mutually exclusive, thus one situation can tackle various practical insights at once. In the following paragraphs, we describe the evaluation of the team with the help of the seven ethical principles as originally formulated by Banks et al. (2012, Banks et al. 2013).

Table 2. Practical insights for Participatory Action Research, based on the joint operationalization of the seven ethical principles of ICPHR by a research team with (young) adults with Developmental Language Disorder.

Aims	Actions
Mutual respect	Participants listen to each other with respect; every opinion and feeling is welcome, even if you don't always agree
<i>Diversity</i> ^a and inclusion	Being a strong team <i>because of</i> the differences in experience, knowledge and views, and because of the ability to adjust to each other's abilities
Democratic participation	Most decisions are made as a team and all participants contribute according to skill, interest and collective need
Active learning	Participants actively learn from each other by both sharing and looking at each other's perspectives
Making a difference	Participants take action with different groups, including local councils, professionals and fellow researchers, to achieve their goals
Collective action	Participants agree on how and when they act together to make a positive change
Personal integrity	Behaving reliably while acknowledging and taking up multiple roles and relationships (friends, peers, colleagues, counselor) ^b

^aEquality has been replaced with diversity (see 1.2 for an elaboration).

^bThe text in bold is added to include the different roles of the (co-)researchers (see 1.7 for an elaboration).

Mutual respect

The principle of *mutual respect* is originally defined as ‘developing research relationships based on mutual respect.’ During the evaluation session, the co-researchers spoke of *actions* and *attitudes* that they found respectful. Meike reassured: ‘We listen to each other; every opinion is welcome. With respect. Even if you don’t always agree. Every now and then emotions are present, but that’s okay.’ Maartje expressed that *mutual respect* also includes the attitude of being sensitive for these feelings: ‘We respect each other’s feelings; we ask how the other is doing. We take the other into account when he or she feels less.’

Jérôme started by giving a more abstract definition of mutual respect: ‘when researchers, co-researchers and the participants and all people involved treat each other with the right principles so that no ethical problems occur.’ When he was asked to clarify, he spoke of *attitudes*: ‘if everyone is treated with the best intentions, with friendliness, and that you accept one another as you are, ... that everyone is different.’ He then positively judged the team and referred to their *actions*:

On a scale of one to ten, yes, I think actually just ten! I think we really do, and I also see that among the participants. We let everyone finish. We give everyone the floor. No nasty remarks to each other. So it’s really the respect that you see in the group and that’s really very nice. We just give each other space to tell your story.

The scientific researchers agreed with this evaluation of respect. Nevertheless, Karijn felt she sometimes failed, especially if she couldn’t pay enough attention to the questions of co-researchers: ‘If the co-researcher asks help and I’m too busy, then it doesn’t always feel respectful.’ Maartje comforted Karijn, ‘it doesn’t mean you don’t respect me [when this happens]. I think, sometimes it’s just like that, that’s not disrespect.’

Equality and inclusion

The principle of *equality and inclusion* is originally defined as ‘encouraging and enabling people from a range of backgrounds and identities ... to lead, design and take part in the research.’ When co-researcher Maartje looked at this principle, she dug into her memory, ‘I can’t remember a moment that we did *not* do that, it doesn’t come to mind.’ Meike positively judged the team: ‘The co-researchers have a big role in the project. We feel equal in the team.’ However, when Covid hit, researchers and co-researchers alike, worried about the ability of the co-researchers to work online. Jet recalls: ‘We all thought, this would be the end of the project, that it would never work. Our prejudices were pretty strong.’ It took efforts for some co-researchers to adjust to unwritten etiquette for working online. For example, Maartje struggled to be consistently present during the online sessions. During one of the first sessions, she said she still had to take a shower, switched off her screen, and a while later she came back online while preparing her breakfast.

The question for the team was, considering the principle of inclusion, whether people should be allowed to participate their own way, by switching off their camera whilst still being audible and taking spontaneous breaks. Another question, for the scientific researchers, was whether they would address these issues in a joint evaluation or in a one-

on-one conversation, and whether they would address the person as an ‘equal colleague’ by giving space for this behavior, or as a ‘student’ by giving instructions on how to be present. By jointly discussing these frictions, the team gradually got more used to the setting, and adjusted to each other, whereas some weeks were better than others. Later in the process, the developed patience for attentively listening to one another was noted by a colleague from another department who joined one of the sessions to exchange ideas. She spontaneously remarked, ‘I have never experienced such a pleasant and peaceful online meeting where people let each other talk.’

When the team started having a full agenda, there was concern that it could become too much for the co-researchers. Jérôme, Maartje and Meike were taking part both as co-researchers and respondents, therefore all the time they were working on all these topics which related to their private lives as well. Meike admitted that the project sometimes took a toll:

[Our work] is very intense, a lot [of experiences living with DLD] comes very close to me. We Zoom a lot, and speak with so many colleagues. And I don’t have a clear division between my work and private life. . . . [Sometimes] I feel I’m getting tired of it. It’s hard for me. It’s about yourself, anyway.

The team learned that, to fulfil the principle of equality and inclusion, they had to find ways to deal with confronting themes. During the sessions of analysis, there was room for the (co-) researchers to reflect on how data resonated with their own experiences, while ensuring that the experiences of the respondents remained the center of attention. Further, the team agreed to take enough breaks during and in between their sessions so that the co-researchers were better able to contribute without getting exhausted. The team members emphasized that it should not be considered a problem if each member has different abilities. We should value these differences, as one of the scientific researchers pointed out: ‘We’re not equal and we don’t have to be; it is the differences in experience, knowledge and views that make us a strong team. I think we do strive for *diversity* and inclusion.’ This is also depicted in the next principle of democratic participation.

Democratic participation

The principle of *democratic participation* is originally defined as ‘Encouraging and enabling all participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need.’ This includes a) *communicating in language everyone can understand, including arranging translation or interpretation if required*, and b) *using participatory research methods that build on, share and develop different skills and expertise*. First of all, the team discussed how to interpret this principle, e.g. does *democratic participation* mean that only the majority dictates what will be done? Or should a minority have a say here as well? The team jointly reflected on situations on how decisions are being made and how they view this.

For example, when the team took time to discuss each person’s contribution to each phase, and looked at the duty *financial administration*, co-researcher Meike answered ‘Jet can do that,’ expressing that she found it self-evident for the program manager to make financial decisions. The same counted for various other steps, like fundraising and

chairing the weekly meeting and writing the minutes. Co-researcher Jérôme explained: 'We discuss well together and try to make most decisions as a team. It's not that everyone has to be involved in every choice what's going to happen. The project leader needs to make the final decision.' Jet agreed: 'everyone has a say in our team. I do think that on some topics, one person's voice counts more than another's. Is that a bad thing?' The co-researchers' voice was often valued most helpful. For example, they could judge best whether an invitation was written in understandable language for young adults with DLD.

On the other hand, several times there was tension regarding whether the co-researchers could decide for all respondents. For example, when the team decided to work with an illustrator to draw cartoons about the participant's traumatic experiences, co-researcher Meike preferred that firstly only the co-researchers would make cartoons. She firmly noted: 'The respondents shouldn't do that yet. Not yet. Maybe later, after we've done our first presentation.' At the same time, a respondent was impatiently waiting for her story of sexual abuse to be drawn. The research team discussed whether new initiatives such as drawing cartoons should only be done with co-researchers, or also with respondents. The team did not come up with a fixed rule, but decisions were made per situation, based on the available means and requests from the respondents themselves.

Active learning

The principle of *active learning* is originally defined as 'seeing research collaboration and the process of research as providing opportunities to learn from each other.' This includes a commitment to 'sharing responsibility for interpreting the research findings and their implications for practice.' When analyzing this principle, co-researcher Meike brought up that they need one another in their learning: 'We are very dependent on each other in this project.'

In first instance, *active learning* meant to the co-researchers that they could ask for help if they took up a task they were not familiar with. For example, they also wanted to transcribe interviews. When they noticed it was too tough for them, they requested the scientific researchers to take it over. Co-researcher Meike sometimes found it difficult to wait for help: 'I finished a report and then I wanted feedback from others but had to wait for two days.' Scientific researcher Iris responded that her silence sometimes hides her own active learning from Meike: 'by not being present I can also learn [from your report], we also have to take into account how many work hours we have available.'

Second, the co-researchers encountered a tension of wanting to be busy while also needing enough time to process information and to give their contribution. 'Sometimes we want to discuss too much. Then I can get a full head, or I feel frustrated. But being very busy also makes the project big fun, we don't have to be bored!' (Meike). In these situations, Maartje asks others to support her to keep up with the others:

We learn something new every time, the whole team does. That's what I like best about this project. . . . Like today, if I really can't do it anymore, then I can really say so. Then someone can help me out, so that I don't miss out in any way.

Lastly, the team members actively learned from each other's perspective. For example, the research team reflected on advice from respondents not to look too decent when applying for social support: 'Don't do your hair up and wear sweatpants.' Co-researcher Jérôme reported afterwards: '[Applying] for social support ... was a pain in the neck for many participants. One even mentioned that you need to pretend to be different to who you are. Then you get more chance of support.' One of the scientific researchers noted it could be considered as lying. In her defense, co-researcher Meike responded, 'it's not about lying, it is about choosing what you tell and what you keep to yourself.' By evaluating this principle of *active learning*, the team became more aware that by jointly analyzing the data, they gained not only more awareness of the perspectives of the respondents, but also of how they enact their own lives.

Making a difference

The principle of *making a difference* is originally defined as 'promoting research that creates positive change for communities of place, interest or identity.' The research team perceived this as 'taking action'; 'because we do research and take action, we do feel we can make a difference.' Co-researcher Maartje was convinced that they had already made this difference: 'We've already achieved having [young] adults with DLD talk with other [young] adults with DLD. That's so much more than being alone or talking only to parents or family.' Meike wrote that the use of Jamboard may have contributed to respondents opening up about bullying and abuse, an important but till then private kept topic:

The participants ... used Jamboard more than other times. Maybe that felt safer, more comfortable to them. ... A lot of emotions were released, including tears, that we even took a break. This way they could let it sink in, and then switch to the tips and solutions.

The tips they gave one another were based on their personal experiences, such as asking help from colleagues when they cannot keep up with the speed, and pretending to be different to the local officer when applying for social support. The team also spoke of the difference they make by working together with the local councils to bring about positive changes based on the challenges in the social domain:

Our aim is precisely to make a difference and we feel that we are succeeding. We as researchers feel very involved with the project. We also work together with different groups to achieve as much as possible. This includes local councils, participants, professionals, and fellow researchers. Working together helps to achieve our goal (Jérôme).

Collective action

The principle of *collective action* is originally defined as 'Individuals and groups working together to achieve change.' This includes 'working for agreed visions of how to share knowledge and power more equitably and promote social change and social justice.' Here the question was whether we found agreement on *how* and *when* we would collectively act. During our project the co-researchers and scientific researchers expressed a desire to start acting already during the process of analyzing, but this still left room for debate.

Should all data be well analyzed so that actions represent all involved young people with DLD, or should we leave room for individuals to take action in advance?

Co-researcher Meike preferred to quickly make an appointment with the social councils, to speak about her personal experiences and what she thinks needs to be done. As an experiential expert, she found it hard to work as a co-researcher who acts with and on behalf of the respondents in the process rather than only speaking for herself. After the first findings were written up and published in several media channels, the co-researchers began to speak more about the experiences of both themselves and the other respondents.

Briefly after the findings were launched, a respondent – whose story about sexual abuse was published as well – expressed her gratitude (using words and emoticons): ‘Wanted to let you know that I really find it great what you do! It feels good that you mean so much to us in DLD etc . . . really great respect’. While the respondent gave credit to the research team, it clearly concerned an outcome of a genuine process in which she greatly contributed to the collective action with the research team, and fully deserved the credit in person.

Personal integrity

The principle of *personal integrity* is originally defined as ‘Participants behaving reliably, honestly and in a trustworthy fashion.’ This includes ‘being open to challenge and change, being flexible and prepared to work with conflict.’ Here the question was how to deal with the regularly encountered tension regarding the various positions of the researchers. For example, the co-researchers struggled with their multiple roles of being a researcher, respondent as well as being friends with the respondents. Even after the transcripts were anonymized, the co-researchers could sometimes guess whose intimate experiences they were analyzing. This made them sometimes feel uncomfortable, but the discomfort became less when they realized that also their own intimate experiences were jointly analyzed. They often did not hide it if theirs was analyzed: ‘Is this me? It could be me.’

Scientific researchers sometimes also shared personal experiences in their interaction with co-researchers and respondents. For example, if Karijn felt that a respondent wanted to open up about a trauma but hesitated, she briefly mentioned understanding the struggle to speak about traumatic issues, adding something relatable about herself. For example, that she needed a long time to find courage to speak up after her boyfriend had crossed her boundaries. She noticed that respondents would then feel more at ease to also confide their trauma. Two respondents who had opened up about sexual abuse to her, approached her afterwards to ask for mental support. One of them was co-researcher Meike. She wrote about her reason to open up to Karijn and how she decided to utilize her experience in the research project:

In private, something moved me that made me want to talk about [sexuality and abuse]. . . I felt I could approach Karijn because of her own experiences . . . and because she is also involved in this at work. After talking to her about it, I put it down on paper. . . You especially want to share it with the target group DLD and they are visual thinkers. I thought if you make illustrations of it, it would also come across as more light-hearted. . . It felt good for me to do this, because I had a goal in mind.

A few months later the research team attended a congress to present their findings on bullying and abuse. As Karijn presented the findings, the co-researchers spoke about their personal experiences relating to the themes. To Meike's surprise, a colleague, who is a psychologist, afterwards showed concern for the contribution of the co-researchers. Meike wrote how this protective care affected her:

There were very nice responses from the audience, such as 'We can't clap on this, it's so touching.' [Later,] we heard that a colleague ... was worried. Were the co-researchers protected enough? I replied that [her concern] hit me with frustration. ... We are no longer clients, but colleagues. ... For us, the conference felt like a great opportunity with good timing, which we certainly did not regret.

Jérôme, like Meike, appreciated the psychologist's concern and soon thereafter had a chat with her. He reassured his colleague, 'the situation will never disappear from my memory, but by sharing [my experience with bullying], first with the illustrator, and thereafter with the audience, has made this memory lighter.'

Despite this appreciation to be able to open up about their traumatic experiences, one question lingers: how can the researchers ensure that their questions are not too confronting, painful and/or harmful? And should the research team firstly ensure that there is professional support available in case it is required afterwards? Or is it enough to refer them to their physician? Whereas the difficulty of dealing with multiple roles was often discussed in the team, it was not covered by evaluating the research process with the help of the seven principles. When discussing the article with critical friends the insight emerged that it could be categorized under *personal integrity*, as it is about how to be *flexible* while taking up different, sometimes *conflicting* roles.

Discussion Lessons learned from using the principles

The purpose of this article was to explore how the seven ethical principles for PHR help researchers and co-researchers to reflect on their ongoing research practice, and in particular co-researchers with DLD. The principles were defined with an awareness of the precariousness of the context in which PAR is practiced, aiming for an understanding of the complexity of participatory research, the ability to tackle ethical challenges, and to encourage institutions to modify their existing values, requirements and ways of working, also with respect to people with cognitive impairments (Banks et al., 2012, Banks et al. 2013; Banks and Brydon-Miller 2019).

The research team of three scientific researchers and three co-researchers decided to jointly develop and publish a Dutch research report in order to do justice to the meaningful participation of all. Further, they regularly took time to reflect on their approach. They learnt that the ethical principles were not only relevant but also an encouragement to critically evaluate the collaboration and its intended and unintended outcomes. Adjustments were made to overcome three difficulties with regard to applying this framework in practice with co-researchers with DLD. Together with critical friends (cf. Kember et al. 1997), these difficulties have been analyzed and discussed.

First, the team encountered the difficulty for co-researchers with DLD to grasp the meaning of the seven ethical principles due to the abstract language that is being used to formulate these principles. As a solution, the team jointly unraveled and redefined the

meaning of the principles and how to put them into practice. The principles were consequently rewritten in easier to understand *practical insights* with concrete aims and actions. These newly defined practical insights may have lost some of the nuance of the principles, but also added nuance as it included the perspective of the co-researchers with DLD. The concept thus became more of use for them to actually participate in the ethical dialogue.

The second difficulty for the co-researchers was to critically reflect on the actual research process during the planned evaluation sessions. Their first, perhaps overly positive, evaluation conveyed that the co-researchers seemed easily satisfied. They noticed that they had not experienced a similar kind of influence or voice in a group before, such as having the power to jointly decide how the research project was to be carried out. It was as if they had stepped into a *warm bath*. For a more nuanced and critical evaluation of the co-researchers, time and effort was needed, e.g. by reminding co-researchers of specific moments of discomfort and excitement in the collaboration, like when they wanted to contribute to transcribing interviews, but felt discouraged when they noticed it was too difficult to do so. Even if space is created for inclusion in all research phases, sometimes it remains difficult to fully include persons with cognitive impairments (Balcazar et al. 1998).

The third difficulty is that the ethical issue of 'Blurring the boundaries between researcher and researched, academic and activist' (Banks et al. 2013, 267) can easily be overlooked. While the ethical issue of the multiple roles is elaborately discussed by various researchers (e.g. Banks et al., 2019; Orne and Bell 2015; Keenan et al. 2017; MacFarlane and Roche 2019; Hersh, Israel, and Shiggins 2021), the seven ethical principles do not clearly define how to act as a research team encountering this ethical issue. Therefore, it was afterwards included in the formulation of the practical insight *personal integrity*: 'behaving reliably while acknowledging and taking up multiple roles and relationships (friends, peers, colleagues, counselor).'

One of the lessons learned is that these blurred boundaries between the multiple roles need to be handled with sensitivity. These multiple roles can take a toll, not only on the respondent and the co-researcher, but also on the scientific researcher, as they put in a lot of emotional work. All researchers are deeply involved, not only in interaction with the respondent, but also during individual moments of analysis and writing. Recounted traumatic experiences of the respondents be an occurring aspect of that interaction. Responsiveness to these sensitive situations thus needs to be seen as an integral part of the ethical insight of mutual respect: 'participants listen to each other with respect; every opinion and feeling is welcome, even if you don't always agree.'

To overcome these three difficulties of evaluating the research process, research teams need to take enough time, space and patience to critically reflect on the ethical issues which are inherent to any PAR project. It needs to be felt by all stakeholders that joint evaluations benefit the whole research project. In case the co-researchers feel challenged to connect ethical principles to concrete situations, the project leader can support or facilitate them by bringing in complex situations they encountered and ask them whether the team acted 'right' according to their own perspective, or if they prefer to do it differently next time. This way, team members are encouraged to share more *concrete practical points* based on their own experiential expertise, rather than having to respond to abstract principles that are difficult to grasp.

As a follow up to the evaluation, the research team can utilize their own developed practical insights during subsequent meetings. This way they can reflect what works best and, where necessary, they can adjust their insights. Ideally this is an iterative process. The practical insights will then gradually come to life, because they will be related to concrete situations that the team has experienced together. Rather than depart from a specific notion of the good, this bottom-up approach is better suited in formulating how an ethically sound PAR project might consequently be envisioned by *all* stakeholders, whereby any concomitant practical insight is not fixed, but continues to develop through the lessons learned. Finally, this study did not depart from a specific norm or notion of what is (or ought to be) ethical, because it does not conceive of good ethical practice as something static or a-historical (cf. Pols 2010; Niemeijer 2015), as the ethical content of practices might itself be comprehended as ‘a way to be normative’ (Willems and Pols 2010, 163). In fact, even (the supposedly neutral practice of) ethics and moral reasoning as such might not be conceived of as value free, but instead as context sensitive, serving multiple interests (Walker 2007; Leget 2013; Niemeijer 2015). Ethical *principles* are thus perceived as abstract and prescriptive in all of its detail (Tronto 1993, 11–12).

We therefore conclude that we need to use terminology that leaves enough room for research teams to formulate for themselves how they can work best. Several terms, such as critical insights (Leget, Van Nistelrooij, and Visse 2017), ethical considerations (Hersh, Israel, and Shiggins 2021) and ethical qualities and parameters (Tronto 1993) relating to how to work together with the people involved concretely and democratically might be more appropriate. However, considering our practical approach, we have chosen the term *practical insights*, as it illuminates that these insights are based on learning by doing and are not fixed, but build on (good) practices, whilst still allowing enough room for adjustments to the particularities inherent to each research process.

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Geolocation information

This concerns a research project in the Netherlands, due to the covid restrictions mainly done online, with scientific and experiential experts from various parts of the country.

Data availability statement

The raw data of this research project cannot be shared due to ethical reasons.

Disclosure statement

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References

- Abma, T., S. Banks, T. Cook, S. Dias, W. Madsen, J. Springett, and M. T. Wright. 2019. *Participatory Research for Health and Social well-being*. Cham: Springer International Publishing.
- Aussems, K., J. Isarin, A. Niemeijer, and C. Dedding. (Manuscript Submitted for Publication). "Stumbling Towards Independent Living: Participatory Action Research with Young Adults with Developmental Language Disorder".
- Balcazar, F. E., C. B. Keys, D. L. Kaplan, and Y. Suarez-Balcazar. 1998. "Participatory Action Research and People with Disabilities: Principles and Challenges." *Canadian Journal of Rehabilitation* 12 (2): 105–112.
- Banks, S., A. Armstrong, K. Carter, H. Graham, P. Hayward, A. Henry, . . . A. Strachan. 2013. "Everyday Ethics in community-based Participatory Research." *Contemporary Social Science* 8 (3): 263–277. doi:10.1080/21582041.2013.769618.
- Banks, S., and M. Brydon-Miller. 2019. *Ethics in Participatory Research for Health and Social well-being Cases and Commentaries*. London: Routledge.
- Boylan, A. M., L. Locock, R. Thomson, and S. Staniszevska. 2019. "About Sixty per Cent I Want to Do It": Health Researchers' Attitudes To, and Experiences Of, Patient and Public Involvement (Ppi)—a Qualitative Interview Study." *Health Expectations* 22 (4): 721–730. doi:10.1111/hex.12883.
- Bradbury, H. 2015. *The Sage Handbook of Action Research*. 3rd ed. Sage.
- Centre for Social Justice and Community Action; National Co-ordinating Centre for Public Engagement. 2012. *Community-based Participatory Research. A Guide to Ethical Principles and Practice*.
- Conti-Ramsden, G., K. Durkin, U. Toseeb, N. Botting, and A. Pickles. 2017. "Education and Employment Outcomes of Young Adults with a History of Developmental Language Disorder." *International Journal of Language & Communication Disorders* 53 (2): 237–255. doi:10.1111/1460-6984.12338.
- Dedding, C. 2013. *Kinderen En Jongeren Actief in Wetenschappelijk Onderzoek: Ethiek, Methoden En Resultaten van Onderzoek Met En Door Jeugd*. Houten: Lannoo Campus.
- Dedding, C., N. S. Goedhart, J. E. Broerse, and T. A. Abma. 2020. "Exploring the Boundaries of 'Good' Participatory Action Research in Times of Increasing Popularity: Dealing with Constraints in Local Policy for Digital Inclusion." *Educational Action Research* 29 (1): 20–36. doi:10.1080/09650792.2020.1743733.
- Dedding, C., B. Groot, M. Slager, and T. Abma. 2022. "Building an Alternative Conceptualization of Participation: From Shared Decision-making to Acting and Work." In *Educational Action Research*, 1–13.
- Freire, P. 1982. "Creating Alternative Research Methods: Learning to Do It by Doing It." In *Creating Knowledge: A Monopoly? Participatory Research in Development*, edited by B. Hall, A. Gillette, and R. Tandon, 29–37. Toronto: Participatory Research Network.
- Gibbs, L, K Marinkovic, A.L Black, B Gladstone, C Dedding, A Dadich, S O'Higgins, et al. 2018. *Kids in Action. Participatory Health Research with Children*.
- Greenwood, D. J., and M. Levin. 1998. *Introduction to Action Research: Social Research for Social Change*. SAGE.

- Groot, B. C., M. Vink, A. Haveman, M. Huberts, G. Schout, and T. A. Abma. 2018. "Ethics of Care in Participatory Health Research: Mutual Responsibility in Collaboration with co-researchers." *Educational Action Research* 27 (2): 286–302. doi:10.1080/09650792.2018.1450771.
- Hersh, D., M. Israel, and C Shiggins. 2021. "The Ethics of Patient and Public Involvement across the Research Process: Towards Partnership with People with Aphasia." In *Aphasiology*, 1–27. Taylor & Francis.
- International Collaboration for Participatory Health Research (ICPHR). 2013. *Position Paper 2: Participatory Health Research. A Guide to Ethical Principles and Practices*. Berlin: International Collaboration for Participatory Health Research.
- Isarin, J. 2012. "SprakSaam." In *Jongeren Met Een Taalstoornis Spreken Zich uit*. Onderzoeksverslag van SprakSaam-PAR: participatie, ervaringskennis, empowerment.
- Isarin, J. 2021. "Wat En Wie: Over Classificatie." *Taal En Identiteit. Tijdschrift voor Neuropsychologie. Jaargang* 16 (2).
- Keenan, J, F Poland, P Wilson, E Mathie, J Boote, A Varley, H Wythe, et al. 2017. "Research Design Boundaries for Qualitative Research and Patient and Public Involvement, and Why They Matter." In *Qualitative Health Research Network Symposium*. 30 Guildford Street, London: UCL, Institute of Child Health WC1N 1EH.
- Kember, D., T.-S. Ha, B.-H. Lam, A. Lee, J. C. K Yum, J. C. K Yum, and Jessie C.K. Yum. 1997. "The Diverse Role of the Critical Friend in Supporting Educational Action Research Projects." *Educational Action Research* 5 (3): 463–481. doi:10.1080/09650799700200036.
- Law, James Boyle, and A Frances Harris. 2000. "Prevalence and Natural History of Primary Speech and Language Delay: Findings from a Systematic Review of the Literature." *International Journal of Language & Communication Disorders* 35 (2): 165–188. doi:10.1080/136828200247133.
- Leget, C. 2013. "Analyzing Dignity: A Perspective from the Ethics of Care." *Medicine, Health Care and Philosophy* 16 (4): 945–952. doi:10.1007/s11019-012-9427-3.
- Leget, C., I. Van Nistelrooij, and M. Visse. 2017. "Beyond Demarcation: Care Ethics as an Interdisciplinary Field of Inquiry." *Nursing Ethics* 26 (1): 17–25. doi:10.1177/0969733017707008.
- MacFarlane, A., and B. Roche. 2019. "Blurring the Boundaries between Researcher and Researched, Academic and Activist." In *Ethics in Participatory Research for Health and Social well-being Cases and Commentaries*, edited by S. Banks and M Brydon-Miller. London: Routledge.
- Niemeijer, A. 2015. *Exploring Good Care with Surveillance Technology in Residential Care for Vulnerable People*. VU University Press.
- Orne, J., and M. M. Bell. 2015. *An Invitation to Qualitative Fieldwork: A Multilogical Approach*. New York, NY: Routledge.
- Pols, J. 2010. "The Heart of the Matter. about Good Nursing and Telecare." *Health Care Analysis* 18 (4): 374–388. doi:10.1007/s10728-009-0140-1.
- Reason, P., and H. Bradbury. 2008. *The Sage Handbook of Action Research: Participative Inquiry and Practice*. (2nd ed. SAGE.
- Stapleton, A., and P. Mayock. 2022. "Structured Ethical Reflection as A Tool to Recognise and Address Power: A Participatory Action Research Study with Separated Young People in France." In *Educational Action Research*, 1–21.
- Tomblin, J. B., N. L. Records, P. Buckwalter, X. Zhang, E. Smith, and M. O'Brien. 1997. "Prevalence of Specific Language Impairment in Kindergarten Children." *Journal of Speech, Language, and Hearing Research* 40 (6): 1245–1260. doi:10.1044/jslhr.4006.1245.
- Tronto, J. C. 1993. *Moral Boundaries: A Political Argument for an Ethic of Care*. Routledge.
- Tronto, J. C. 2013. *Caring Democracy: Markets, Equality, and Justice*. New York: New York University Press.
- Vissers, C. T. W. M., J. Isarin, D. Hermans, and I. Jekeli. 2021. *Taal in Het Kwadraat: Taalontwikkelingsstoornis: Kinderen Met Tos Beter Begrijpen*. Huizen: Pica.
- Walker, M. U. 2007. *Moral Understandings: A Feminist Study in Ethics*. Oxford University Press.
- Willems, D., and J. Pols. 2010. "Goodness! The Empirical Turn in Health Care Ethics." *Medische Antropologie* 22 (1): 161–170.