Chapter 7

Inclusion of Children With Refugee Backgrounds in Research

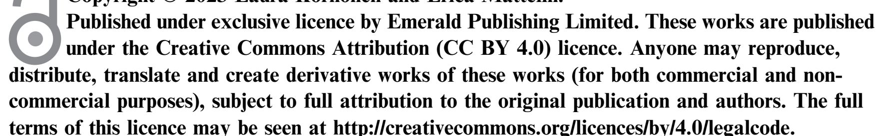
Laura Korhonen and Erica Mattelin

Abstract

The population of internationally forcibly displaced people, which includes refugees and asylum seekers, is large and heterogeneous. To determine the varying reasons for and experiences during the migration journey, including exposure to violence and health- and integration-related needs, there is an urgent need to involve children with refugee backgrounds in research and development activities. This chapter describes a model for the child participatory approach developed at Barnafrid, a national competence centre on violence against children at Linköping University in Sweden. The model has been tested in the *Long Journey to Shelter* study, which investigated exposure to violence and its consequences on mental health and functional ability among forcibly displaced children and young adults. As part of this project, we conducted workshops with children (n = 36, aged 13–18 years) to design a questionnaire on exposure to community violence in the country of resettlement. Experiences recounted during the child participatory workshops indicated no problems involving newly arrived children with refugee backgrounds and Swedish-born adolescents in research activities. However, attention should be paid to proper preparatory work and the need for adjustments. We discuss the results in light of other studies on refugee child participation, the United Nations Convention on the Rights of a Child and diversity considerations.

Keywords: Forcibly displaced; refugee children; Barnafrid child participatory model; children's rights; action research; violence

Participatory Research on Child Maltreatment with Children and Adult Survivors, 113–127



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doi:10.1108/978-1-80455-526-220231008

Introduction

Current statistics show that approximately 100 million people are displaced worldwide, half of whom are children (UNHCR, 2022). This group is very heterogeneous (UNHCR, 2021) and includes, among others, refugees and asylum seekers (hereafter referred to as children with refugee backgrounds). For example, causes for and experiences during migration vary greatly and may include travelling long distances and staying at refugee camps and reception centres. Children with refugee backgrounds may also experience many types of adversities, including violence at one or more stages of the migration process (Itani et al., 2014; Jud et al., 2020). Children fleeing war or armed conflicts might also have extremely severe exposure to war-related violence such as bombing, torture and hostage-taking (Shenoda et al., 2018). War may force children, even very young children, to flee unaccompanied or unwillingly separated from their guardians, exposing them to a heightened risk of violence, abuse and exploitation (Jensen et al., 2015).

The effects of exposure to violence and other adverse events are well documented but differ from one person to another (Gilbert et al., 2009). Among refugee and asylum-seeking children worldwide, an estimated 23% are affected by posttraumatic stress disorder, 14% by depression and 16% by anxiety disorders (Blackmore et al., 2020). Many children also have specific needs regarding their physical health (Baauw et al., 2019).

A systematic review of risk and protective factors for mental health concluded, among others, that no or low exposure to violence, stable settlement and social support was associated with better outcomes in the country of settlement (Fazel et al., 2012). However, substantial gaps remain in knowledge on risk and protective factors for health-related consequences (Mattelin et al., 2022). Also, access to health-care services, support and treatment based on individual needs during different phases of the migration journey need to be elucidated in more detail to tackle known health inequalities (Lebano et al., 2020).

Participation and Agency Among Children With Refugee Backgrounds

Children with refugee backgrounds are often labelled as passive and vulnerable victims dependent on adults (White et al., 2011). At the same time, many individuals are resilient and can prosper after hardships (Marley & Mauki, 2019; Masten & Narayan, 2012). Also, agency – an individual's intrinsic capacity for intentional behaviour developed in their environment and subject to environmental influences (Thompson et al., 2019) – is vitally important to recognise to allow children to participate and foster resilience.

The Convention on the Rights of the Child (CRC) also emphasise that children are social actors by stating that all children have a right to be heard (United Nations, 1989). However, many factors challenge this right (Coyne, 2010). For example, children's competence to participate in research can be underestimated; some might fear that participation might harm the child, especially when the research concerns complex topics such as violence; and others perceive children

with refugee backgrounds as difficult to recruit and retain. Practical concerns such as language barriers, the need for child safeguarding policies and sufficient resources may also limit interest in involving children. Due to these reasons, children are most often engaged as passive participants in research rather than active contributors (Hill, 2006).

A recent scoping review studied children and young people's participation in developing interventions for health and well-being (Larsson et al., 2018). None of the studies included refugee populations, and child involvement was not fully developed to a higher level of participation in most of the studies. Even if studies reported an ambition to increase children's involvement in the research process, this was seldom evident when analysing the results.

However, participatory action research has been successfully used in community-based programmes (Knightbridge et al., 2006). For example, the method has been used to study emotional and behavioural problems exhibited by Somali Bantu and Bhutanese refugee children in the United States (Betancourt et al., 2015). A similar approach involved Afghan families in a research project about their experiences with maternity and early childhood health services in Australia (Riggs et al., 2015). In some studies, both refugees and health-care workers were involved in understanding health needs, barriers and wishes (van Loenen et al., 2018).

These examples align with the results of a recent scoping review of the participation of refugees in community-based participatory research in health care (Filler et al., 2021). This review found 14 studies, and the refugees involved in these studies participated in different stages of the research process, most often in the study's design, recruitment, data collection and knowledge translation and dissemination. No study involved refugees in obtaining grants. Engagement in data analysis, article writing and upscaling initiatives was less frequent.

Apart from community-based participatory research, focus group interviews have been used to study health literacy among immigrants and refugees (Tiedje et al., 2014) and find solutions to child marriage (Freccero & Taylor, 2021), among other topics. Furthermore, the patient and public involvement approach with 'refugee advisors' has been used in the development of a study design to investigate a brief group intervention for refugee children experiencing symptoms of post-traumatic stress (Warner et al., 2021), among others. This approach has also involved forced migrants in designing the research agenda to reduce the impact of complex emergencies on public health (Brainard et al., 2017). However, models still need improvement to integrate principles and approaches to children's participation with hands-on guidance.

In summary, children with refugee backgrounds have a rich spectrum of experiences. To leverage their diversity and empower these children, participatory approaches are warranted to focus on relevant research questions and advance the field by designing studies that capture the heterogeneity of this group and nuances in the topic of interest (Hearn et al., 2022).

The Barnafrid Model for Child Participation

Theoretical Underpinnings

In keeping with this CRC framework, a key challenge is ensuring that children's involvement is authentic and involves a strong focus on their perception and understanding of the world in which they live (Sommer et al., 2010). This perspective is different from the children's perspective, which refers to attempts to increase the understanding of children's views on the world by reconstructing their perceptions and actions. Although this approach centres on the child, there is a risk that the child is objectified based on the adult's views of children (Sommer et al., 2010). This is increasingly important when it comes to research on violence, in which children might be excluded to an even more significant extent due to the subject's sensitivity.

The participatory approach refers to 'research being carried out "with" or "by" members of the public rather than "to," "about" or "for" them' and engagement being 'where information and knowledge about research are provided and disseminated' (National Institute of Health Research, 2021). Children can be included in research at different stages, as presented in Fig. 7.1. Their participation can vary from consultation to involvement, collaboration and child-led research (International Association for Public Participation, n.d.), depending on the age of the children and their knowledge and experience of specific issues.

Barnafrid, as a national competence centre, wanted to develop a more practical model for child participation in research about violence. Many published models were great in describing why to involve children and the theoretical underpinnings but did not give practical guidance to the researcher. There was

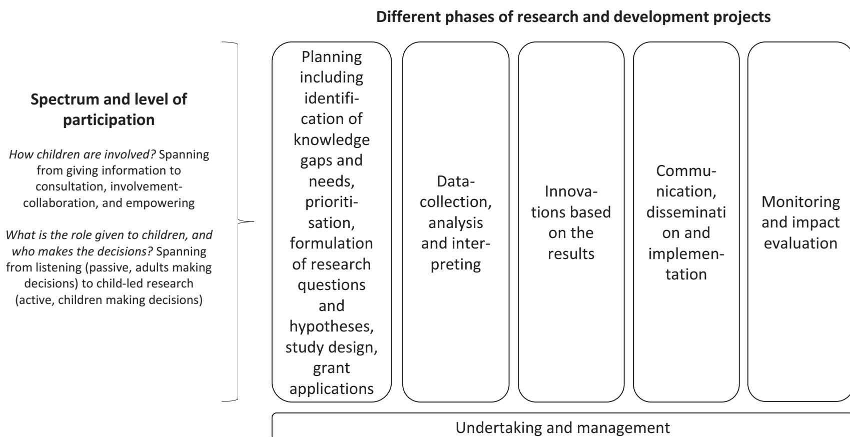

Fig. 7.1. Level and Extent of Child Participation. Children can assume different roles in research projects depending on their needs and possibilities.

also a need for a model that allows flexibility to involve children to a lesser or broader extent and adapt the model depending on their needs. The Barnafrid model acknowledges the CRC and the existing nine principles for the ethical participation of children, as presented in Fig. 7.2 (United Nations, 2009). In addition, it includes aspects and influences from participatory action research, patient and public involvement, childhood studies and evidence on child participation from the nongovernmental sector.

There is also a need to combine expertise in violence against children with that concerning child participation. In this process, children have an indispensable role due to their unique experiences. Overseeing the unique input from children may negatively impact the relevance and quality of the research conducted.

Description of the Model

The model is divided into pre-workshop, workshop and post-workshop stages (Fig. 7.2.).

Stage 1: Pre-workshop Activities. The pre-workshop step is a preparatory stage, and critical actions at this step include:

- Information about and training for those involved in the workshop (adults and children in the role of mentors or observers) in using the model and theories of child participatory research, including the CRC and ethical principles.
- Survey of the child safeguarding plan in the context of the planned activity.
- Booking of a child-friendly space with a possibility for children to move around the room, proximity to toilets and the opportunity to enter the area with prams or strollers. In addition, there should be access to dining and a separate room

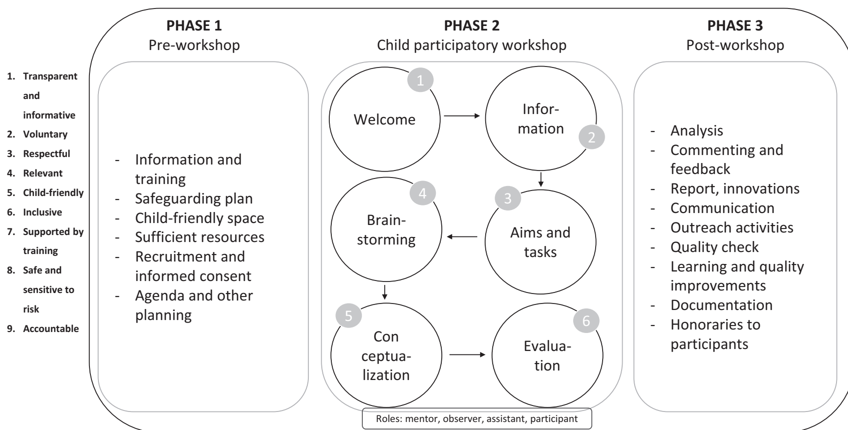

Fig. 7.2. Summary of the Barnafrid Model for Child Participation in Research and Development Activities.

or place where the participants can retreat to gather strength if necessary. A waiting room for accompanying persons is also desirable. Particular attention should be paid to the safety of children, such as fire safety or the risk of fall accidents.

- A plan for required resources and competencies. Usually, a minimum of three people is needed: one mentor for children, one observer who monitors the workshop's quality and gives feedback to the mentor and at least one person who assists the children. The need for tutors and helping people in the workshop depends on the age and background factors of the children.
- A plan for technical devices and other needs. For example, interpreters or alternative communication devices may be required. All materials used in the workshop should be easily followed and child friendly.
- A plan for recruiting children should be established with particular attention to inclusiveness and diversity.
- If necessary, an ethics permit should be obtained (European Union Agency for Fundamental Rights, 2014). Children and their guardians should receive written or oral information about the workshop in a child-friendly way and be able to ask questions. All participants and their guardians also receive a copy of the child safeguarding policy. Participants and their guardians should be asked for their written informed consent. An honorarium may be paid for attending the workshop. The value and form of the honorarium may vary, e.g. depending on the ethics permit and national taxation guidelines. If an honorarium is being paid, the researchers should check appropriate values for each area.
- An agenda for the workshop and booking of catering based on individual needs such as allergies and cultural preferences.

Stage 2: Child Participatory Workshop. The workshop is divided into six steps (Fig. 7.2). In Step 1, children are welcomed and a few 'get to know each other' games are done to facilitate grouping. Subsequently, the workshop mentor (adult or child) explains the practical matters, such as where to find toilets, and goes through the safety measures, including the plan if someone needs help. The roles and responsibilities are clarified, and the workshop agenda is explained. The children are free to ask questions and are assured of how to get more information. In addition, children are informed that they can withdraw at any moment without any explanation.

Subsequently, the mentor gives information about children's rights and participatory research. Also, the ethical principles for child participation are explained and discussed, followed by an exercise in which the participants rank the fundamental principles linked to the value base (e.g. respect and the right to be heard) from most important to least essential to initiate discussion on the priorities, shared principles and rules for the workshop.

This is done in Step 2, in which the group mutually agrees on respecting and adhering to the code of conduct while participating in the workshop. These rules, set by the participants, may include: (a) raising a hand when someone wants to speak up or draw a mentor's attention, (b) not interrupting others, (c) not judging others, (d) having the right to have an opinion and (e) confidentiality.

In Step 3, the mentor presents the workshop aims and introduces the topic, followed by group discussions. Also, methods for the workshop are discussed. At this step, it is possible to allocate additional roles for participants.

In Step 4, the child group starts brainstorming. The methods are flexible and may include individual work, work in pairs or whole-group work. The discussion and knowledge attainment can be initiated by questions, case vignettes, storytelling, role playing, video films, newspaper clippings or pictures (Grace et al., 2019; Larsson et al., 2018), among others. The participants can freely express their thoughts and feelings and share their experiences using different approaches such as think-aloud methods and written feedback mobile surveys (Larsson et al., 2018). The children regulate the degree of participation. The mentor guides the discussions to foster more nuanced talks and consideration of multiple perspectives. The product can be documented, e.g. on paper notes or digital pages.

In Step 5, the children take a break and refreshments are provided. At this point, the produced material is reviewed to conceptualise the input and determine what might be missing. The observer also gives constructive information on the content and work process. After the break, the children discuss the drafted conceptualisation and work more to reach a final agreement on the product.

In Step 6, the participants evaluate the workshop based on the nine ethical principles. Free comments and reflections are encouraged. The participants can also give feedback individually afterwards via a web survey. The observer summarises the observations using a checklist in an impact log. This is distributed via email or social media to the participants.

Stage 3: Post-workshop Activities. After the workshop, the produced material can be further analysed using qualitative and statistical methods. Children are encouraged to participate in this process. The analysed data are returned to the participants for comments. For this purpose, a new workshop can be organised or input collected, for instance, by email, collaboration platforms or videoconferencing discussions. The following steps may include writing a report or producing practical tools, communications and other outreach activities. Stage 3 activities also involve assessing the workshop's quality and identifying improvement needs. Also, honoraria are paid, and children and their guardians are informed about the next steps in the process.

Experiences From Using the Barnafrid Model in the Long Journey to Shelter Study With Refugee Children

Our ongoing study, the *Long Journey to Shelter*, investigates contemporary refugee children and young adults who have arrived in Sweden (Mattelin et al., 2021). The study focuses on exposure to violence and other adversities, mental health and functional ability. Data on social support and resilience are also collected.

The Barnafrid model was used in four workshops to design a questionnaire to study experiences of violence in public places in Sweden.[1] The participating children were 36 high school students aged 13 to 18. The teenagers who participated had mixed nationalities, including newly arrived children with refugee backgrounds and Swedish-born adolescents. They were recruited with help from Save the Children Sweden and via contacts with a refugee centre and schools. We did not experience any problems in recruiting or retaining participants.

On the contrary, young people self-initiated contact and volunteered after learning about the initiative. All participants and their guardians signed informed consent according to the ethical approval process. The workshop participants received a SEK 300 gift card as an honorarium.

Each workshop took 2–3 hours and was led by the staff from Barnafrid, according to the model. When participating children spoke different languages, the workshops were held in English to be inclusive. In some workshops, only Swedish was used. The workshops were held in public places such as schools and libraries. The workshops were adult initiated with predefined topics and research questions. Child participation was limited to the level where children's views were considered. This restriction was done to keep the process simple, ensuring accurate model testing.

To initiate the discussion, the child group discussed what violence looks like in society today and the kinds of violence to which children and young people may be exposed. Their thoughts about the dangers of being exposed to violence as a young person then developed into preventive measures, such as how to detect violence and what support from society is needed after experiences of violence. Subsequently, the participants were divided into groups of three to four people with a task to identify critical words related to violence in public places. Padlet, a virtual bulletin board programme, was used to document the work.

The material produced in the workshops was later analysed using qualitative content analysis (Lundman & Hällgren Graneheim, 2008). Sentence-bearing units were identified, condensed and encoded. The codes were then compared and sorted into themes.

The children described, for example, a concern related to younger children who might be affected by violence in the neighbourhood. One example is when people distribute drugs in the community. Younger children can be lured into this, which concerns older siblings and parents. The lack of safe spaces for youth and small children was of great concern in almost all workshops, particularly in the nearby neighbourhood.

The adolescents also highlighted the vulnerability of children and young adults from different cultural backgrounds. They argued that families with diverse cultural backgrounds might be less integrated into society, and that rumours about violence in society might restrict children from going to public places, hindering

[1]The workgroup included Laura Korhonen, Erica Mattelin, Natalie Söderlind, Frida Fröberg, Hania Kutabi and Sofia Michael.

them from fully participating in the community. Some children described that this can be frustrating and that parents might not trust children, creating conflicts.

The participants described a concern associated with being a child because children depend on parental ability, such as the provision of supervision. Being young is linked to being more easily involved in gang crime or subjected to violence by adults or peers. Home and school are arenas where violence often occurs because of a lack of safety nets. The children also mentioned that adults who are supposed to protect them from bullying, in some cases, also perpetrate racism in schools. They also highlighted that schools often are areas where conflicts start, but that they sometimes move into the community. Participants in one workshop described a concern that conflicts sometimes involve weapons.

The knowledge produced in the workshops was used to draft a questionnaire on violence in public places. The draft was submitted to the children for feedback. Data collection using the questionnaire is ongoing among young adults with refugee backgrounds.

The feedback from the participants was overwhelmingly positive, both in oral and written forms. The participants rated the workshops with an average score of 4.81 (scale of 0–5). Suggestions for improvements were mainly practical.

> The only thing that came to mind right now was that maybe you should have more discussion in a full group. Because we had to discuss in small groups and present it to the whole group, you could discuss it a little longer with the whole group. I think you would come up with more points and be able to develop those points more, and it would also be more interesting to hear everyone's opinions. Then it may have been that time wouldn't have been enough if we had done that, and in that case, it's fine.
>
> However, I find it easier to express opinions by talking instead of writing on Post-it notes.

General feedback indicated that the inclusion of the whole group was satisfactory and that many felt their voices had been heard.

> That the researchers listened to us and understood us.
>
> That we children have the opportunity to express our thoughts about it all and to be rewarded.
>
> The inclusion of us young people. The kindness, niceness, and respect from you and the participating youth. That we were not negatively seen as children and adolescents, but that it was seen as something good. We got to say our opinions and were listened to without being looked down upon. We discussed the actual topic and question (it was an interesting and important topic to discuss) and how you had set it up (writing on the board, discussing in groups, etc.). The staff was amicable and helpful. That we were in

> a safe and suitable room was instructive in several ways (I learned a bit about how a research process works and what research methods can look like, our rights as young people, violence against young people, and what it's like to be involved in a research project, etc.).

The involved staff members emphasised the importance of careful planning and preparedness for unexpected happenings when working with children. Effective use of the model became easier with repeated workshops.

When summarising the work, one identified shortcoming was that the researchers, in many ways, implied that children should want to be heard and that it is culturally relevant to speak up about issues that concern them. One mentor with Arabic-speaking background highlighted the need not to interpret children who were quieter as being less involved but rather that the current Swedish norm for children to act does not apply to other cultures and what we see as appropriate behaviour might be seen as problematic in different contexts. The model was seen as feasible, but cultural aspects must be considered when interpreting the level of participation.

Another point from the mentors was that the children had very different preconditions when entering the workshop, making training of the mentor essential. In our case, the mentors were mainly doctoral students with backgrounds as child psychologists who helped try to meet the group's needs best.

Further, there were barriers in terms of COVID-19. We had planned to give feedback by returning to the place of the interviews. This was not possible due to pandemic-related restrictions and limited the possibility of discussing the outcome (questionnaire) in detail. Although it's unlikely that a new pandemic will hinder others from child participation, the surrounding world has made it painfully clear that we need to be prepared for anything. A mentor recommendation would shorten the time between workshops and feedback as much as possible.

In summary, the Barnafrid model worked well in involving children with refugee backgrounds in research about community violence. The main strength of this approach is that it is more systematic, giving researchers the ability to focus on content rather than structure. Further tests of this approach are needed to guide amendments and the possibility of comparing it to other methods.

Discussion

We have developed a model for child participation in research and development activities and tested the model in four workshops on community violence. The Barnafrid model provides an accountable framework that respects the rights of children and ensures safeguarding, yet allows flexible adaptation and use of the same model at any point of the research process.

Our experiences indicate no problems involving even newly arrived refugees in research activities. However, we noticed that special attention should be paid to providing information to the participants and their guardians, especially if the

children have recently arrived in the host country. The information should be given orally and in written format, preferably translated into the language the family speaks. This requires more time and resources, such as access to interpreters. Involving children in research is rare in many societies; thus, the opportunity to ask questions should be provided on several occasions.

Children with refugee backgrounds were eager to participate, and their guardians were willing to sign informed consent. Unexpectedly, some refugee children took their younger siblings to the workshop because they were responsible for them during the workshop. Due to this, the workshops needed to be adjusted by letting the assisting person take care of the accompanying children while making it possible for the participants to see and support their siblings. Also, adherence to set timetables was flexible.

Previous child participation approaches have featured obstacles to involving children in research projects. These include problems managing group dynamics, children not accepting their assigned roles, under- or overestimation of children's knowledge and their inability to commit to time-intensive activities (Rouncefield-Swales et al., 2021). In addition, it is essential to ensure that children's perspectives are not lost during the research process, which may take several months to years. We also noticed the importance of reducing the time between the workshop and data analysis and reporting as much as possible.

Undoubtedly, the involvement of children with heterogeneous refugee backgrounds significantly added to the knowledge produced in the workshops. The experiences obtained in the *Long Journey to Shelter* study align with previous literature recognising children's vital contributions to research (Hearn et al., 2022). Some participants served as a voice for a larger group of children in the same situation and were keen on raising the issue of violence against children in other contexts. This demonstrates the meaningfulness and relevance of child research participation, going beyond the research project and having a social impact. Participation is a right, according to the CRC, but it also is a way to empower children; strengthen their self-confidence, self-esteem and agency; and facilitate resilience (Clarke, 2015). It also functions as a way of building bridges between newly arrived refugees and the country of resettlement to foster integration.

Implementing a child-participatory approach that pays attention to the heterogeneity of experiences and needs of children with refugee backgrounds is needed in migration agencies, social services, schools and health care (van Loenen et al., 2018). More comprehensive training is needed for professionals to support children's involvement and foster a higher level of child participation. This is also in line with the nine principles for ethical child participation. Separate training is needed for researchers to improve study designs that ensure engagement with children. Also, guidelines and checklists or documentation of child participation in research studies should be used (Staniszewska et al., 2011, 2017), as should quality and impact indicators (Brett et al., 2014). Further development in the field might also facilitate the transition from solely adult-initiated and adult-conducted research to more codesigned studies and production of new knowledge and solutions to urgent problems, such as the current forced mass migration. In the

face of these significant challenges, it is essential to strengthen the understanding of community priorities and via engagement, foster confidence that research and development activities and subsequent evidence-based decision-making pay sufficient attention to the right of children to participate.

Conclusions

The Barnafrid model is simple and can be used in any setting. We hope that this or similar models will facilitate the involvement of children in research and development activities in different sectors of society.

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