Emerald Studies in
Child Centred Practice

Participatory Research on Child Maltreatment with Children and Adult Survivors

Concepts, Ethics, and Methods

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Editors Maria Roth
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Participatory Research on Child Maltreatment with Children and Adult Survivors

Emerald Studies in Child Centred Practice

Series Editor: Sam Frankel, King's University College, Wester University, Canada; Equipping Kids.org

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Participatory Research on Child Maltreatment with Children and Adult Survivors: Concepts, Ethics, and Methods

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INVESTOR IN PEOPLE

This book is dedicated to all children and adult survivors of child maltreatment, in all its forms. The researchers who wrote this book aim to learn from and with you, day by day, in order to improve the quality of the research that is done in this area. We hope we can make a difference and encourage other authors to use participatory research. Your voices and decisions matter.

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About the Editors

Maria Roth, PhD, is a Professor Emerita and Researcher in the Social Work Department of Babes-Bolyai University in Cluj, Romania. Before entering the academic field, she worked with children in special schools, orphanages and hospitals. She developed research and published in the area of child protection; developmental psychology; the well-being of Romanian children and youth; identification and prevention of child abuse and neglect in schools and families; support services for vulnerable children; children's rights; adverse childhood experiences; and programme and service evaluation. Her recent research projects have focused on the social dimensions of school success, service standards in protecting children from abuse and neglect and disadvantaged (Roma) children.

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Hervör Alma Árnadóttir, PhD, is a social worker and has the position of Associate Professor in the Faculty of Social Work at the University of Iceland. She is currently serving as the Head of the Faculty of Social Work. Hervör Alma's main teaching has been on child protection, group- and teamwork and children's participation. The main emphasis of her research has been on participation of children in welfare research. She has focused on research with children living in poverty and has delivered papers about opportunities of children to participate in research and about gatekeepers when researchers seek access to children for participation in welfare research.

Giuseppe Aversa is the Spokesman of The Committee of Minors abandoned by the State to Forteto. In 2009, 12 years after his out of home placement, he was one of the first to report the abuse and maltreatments perpetrated in the residential childcare community where he was collocated. He is a student of social sciences and he contributes to build a participatory chance to be listened to by the professional, social and political contexts through his participation as expert by experience to national and international conferences, training initiatives and discussion forums. Some of his contributions in this field are currently in press. The Committee of Minors abandoned by the State to Forteto that he represents is entirely made of adults who grew up in this residential childcare community where the State entrusted them at an early age in childhood.

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2015, she has been coordinating the projects 'Oltre' and 'Ancora Oltre' for Artemisia, implemented for supporting the social inclusion and trauma recovery of 40 survivors of sexual, physical and psychological violence perpetrated for decades in a big residential childcare community named 'Il Forteto'. Besides the clinical work with adult survivors of institutional abuse, she has conducted the research activity of the S.A.S.C.A. Project, by interviewing the survivors and by participating in the definition of guidelines for social-healthcare workers in front of situations of institutional abuse.

Sinem Cankardas, PhD, is an Assistant Professor in Turkey. She is currently working at Izmir Democracy University, Department of Clinical Psychology. She received her doctorate in Clinical Psychology with a concentration in Psychological Trauma in 2018, following the completion of a pre-doctoral internship at the University of Lancashire. She worked as a Researcher on several European Projects (Balkan Epidemiological Study on Child Abuse and Neglect; Behavior, Security and Culture) and an international project (Safer Together Project/UK). Her research and clinical interests are broadly focused on the areas of interpersonal violence, stress and anxiety-related disorders and cognitive behavioural therapy. She published several articles on child abuse and neglect and effects of gender based discrimination on mental health. She is also the editor of the book titled *Being Women: Gender Based Discrimination and Mental Health* published in 2022.

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Andreas Jud, PhD, has a Chair (tenure-track) on Child Maltreatment Epidemiology at the University of Ulm's department of Child and Adolescent Psychiatry/Psychotherapy, Germany, and is staff at Zurich University of Applied Sciences, School of Social Work, Switzerland. His research focuses on service provision in multiple sectors of the child protection system. As the chair of the pan-European network Euro-CAN on Multisectoral Responses to Child Abuse and Neglect in Europe (COST Action 19106) he coordinates 130+ members in 35 countries and their efforts to improve data collection. Andreas Jud is an Associate Editor of *Child Abuse & Neglect*, the leading international journal in the area of child protection.

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Foreword

Andreas Jud

In a world still full of atrocities, disasters and widespread poverty, there is consensus that children are among the most vulnerable in our societies: As adults, they suffer from the aforementioned phenomena, including victimisation by strangers or peers. In addition, some children are subjected to violence by those responsible for their upbringing: parents and other close caregivers (for a detailed conceptualisation of children's victimisation in multiple settings, see Finkelhor, 2008). This type of violence is commonly labelled *child maltreatment* and encompasses the subtypes of neglect, sexual abuse, physical abuse and psychological maltreatment. Unfortunately, academia and child protection practice have not yet converged regarding a uniform and operationalised definition for child maltreatment; varied definitional approaches are still abundant (e.g. Jud & Voll, 2019). Consequently, epidemiological research on the prevalence of child maltreatment is associated with large variances and lack of comparability (e.g. Jud et al., 2016). Still, findings have unanimously confirmed the large size of the problem: Studies regularly identify that more than 10% of respondents have suffered from violence at the hands of caregivers in their childhood (e.g. Sethi et al., 2015; Stoltenborgh et al., 2015). Despite definitional challenges, there is a steadily growing evidence base on the prevalence of child maltreatment both around the world and in Europe. Empirical information on who gets services and protection by which type of services in a multidisciplinary field, however, is either lacking completely for some countries or lacking relevant variables and reliable coding in others. Additionally, available administrative data on child maltreatment lack comparability across countries. Administrative data, however, are needed to understand how well a child protection system addresses its challenges and serves its vulnerable population, identify potentially underserved populations and unintended regional variances in protecting vulnerable groups and so on (e.g. Jud et al., 2016).

To counter the lack and deficiencies of administrative data in different sectors of child protection systems on the European continent, more than 130 academicians, researchers and professionals from different disciplines in 35 countries have gathered in a network labelled Euro-CAN (http://www.euro-can.org), an acronym for its title: Multi-Sectoral Responses to Child Abuse and Neglect in Europe: Incidence and Trends. The initial 4 years of the network were sponsored by the European Cooperation on Science Technology (COST) as COST Action 19106.

Euro-CAN has established five working groups in an effort to mobilise knowledge in improving data collection on documented incidents of child maltreatment. Working Group 1 focuses on the challenging task to find pathways towards making definitions of child maltreatment more comparable and standardized. Working Group 2 collects information on available administrative data on child maltreatment in Europe and tries to access these data for secondary analyses and comparisons across countries. In close connection with the latter, Working Group 5 tries to elucidate the impact of the COVID-19 pandemic on reported incidents of child maltreatment. It is essential to not only 'preach to the converted' who embrace the importance of data collection on child maltreatment incidents but also advocate for this relevant task among policymakers and administrators who are responsible for data collection. Working Group 4 dedicates its efforts to the communication of our goals and output. The book you have started to read, however, is a valuable output of Working Group 3, which focuses on participatory approaches in epidemiological research on child maltreatment. We are adamant in our convictions that victimised individuals are not to be perceived simply as respondents of surveys or individual data points in records or child files but empowered subjects in research on their suffering. Participatory approaches will improve efforts to better understand how child protection systems work and ultimately, minimise child maltreatment in upcoming generations.

Although the literature on participatory approaches in child protection is – fortunately – trending upward in general, participatory approaches to epidemiological research on child maltreatment are still largely terra incognita. This edited book contributes to mapping the territory in 17 chapters contributed by 36 Euro-CAN members from different countries, disciplines and child protection sectors. The coleaders of Working Group 3, Maria Roth and Ravit Alfandari, together with Gemma Crous have assembled an overview that both highlights gaps and needs and also identifies opportunities and examples of good practice. Excerpts from four chapters give exemplary insight on major takeaways: Filistrucchi et al. (2023) clarify that participatory approaches will not necessarily bring up issues that are entirely new to professionals and academicians in the context; they will, however, always add an additional layer and perspective to better understand and contextualise the complexity of child maltreatment incidents. Having been objectified for a major part of their life, survivors of child maltreatment might once again feel objectified by non-participatory research on child maltreatment and consequently, decline to respond, as Schlingmann (2023) highlights. Giving voice to survivors might thus increase response rates. Participatory approaches, however, move beyond increased response and an improved, holistic understanding of child maltreatment. The ethical component of giving voice to survivors of child maltreatment has the power to contribute a restorative value to epidemiological research on the topic (Filistrucchi et al., 2023). Being heard might thus potentially support a process of healing. In an overview of recent participatory research projects with children on maltreatment, Alfandari et al. (2023) highlight that there is a need not only for more participatory research in general but also for higher degrees of children-led participation. The overview on legal prerequisites in Europe for participatory research with children not only reveals both a large variance in pertinent legislations but also identifies potential barriers for future research on the topic (Ntinapogias & Nikolaidis, 2023).

As the Chair of the Euro-CAN network and COST Action, I strongly recommend that you read this entire book to find additional takeaways, spread and multiply them, and include participatory approaches in your research. Ultimately, this might add a mosaic puzzle piece to minimising children's suffering in the future. As Albert Einstein, the most famous son of the city that hosts my university, allegedly put it: 'There are no great discoveries and advances, as long as there is an unhappy child on earth'.

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Introduction

Maria Roth, Ravit Alfandari and Gemma Crous

General Introduction

This book on 'Participatory research on child maltreatment with children and adult survivors: Concepts, ethics, and methods' aims to explore, develop and share theoretical concepts, ethical considerations and research methods critical to collaborating in research with children and adult survivors of child maltreatment and violence. This introduction highlights the needs of children in contemporary society; provides a brief introduction to concepts underpinning children's participation in society and in research generally; and goes on to identify some key challenges for children's participation in research on the sensitive and painful topics which are the focus of this book. This introduction concludes with a synopsis of how the authors came to be collaborating on this writing venture, and an outline of the three sections and 16 chapters which comprise this book. The book offers a comprehensive and multi-faceted picture of how children and victims' right to express their opinions on the violence affecting them can be effectively gathered and fruitfully applied, using methods and perspectives drawn from various disciplines. We trust that it will be a valuable resource for the development of research, practice, teaching and the management of services.

Needs of Children

Children face a range of detrimental behaviours and acts such as sexual and physical assault, neglect, psychological harm, and witnessing violence in varied settings such as home, schools, community and online (World Health Organization [WHO], 2020a). Accordingly, in this book, we adopt a broad understanding of child maltreatment that covers all forms of physical and emotional ill treatment, sexual abuse, neglect or negligent treatment, or commercial or other maltreatment, and exploitation resulting in actual or potential

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harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power (WHO, 2020b).

Global estimates suggest that more than half of all children aged 2–17 years – or 1 billion children – experienced interpersonal violence in the past year (Hillis et al., 2016). In the European region, an estimated amount of more than 55 million children younger than 18 suffer from child maltreatment, which causes the deaths of 700 children younger than 15 each year (Pritchard & Williams, 2010; Sethi et al., 2013, 2018). The impact of the COVID-19 pandemic on child abuse prevalence is still not fully actualised, yet it is expected that the rates will stabilise at a higher level than before the pandemic (WHO, 2020a).

Interpersonal violence against children by parents or other caregivers, peers or strangers continues to be a serious global public health and social problem (Hillis et al., 2016). Experiences of violence during childhood can bear acute and long-term negative consequences for individuals along the life course, including developmental deficits, mental and physical health problems, poorer educational prospects and reduced earnings from employment, thus imposing profound economic, health and social burden on societies (Sethi et al., 2013, 2018; WHO, 2020a).

The 2030 *Agenda for Sustainable Development*, adopted by all United Nations (UN) member states in 2015, includes an urgent call to action for all countries to eliminate violence against children, as explicitly indicated in Target 16.2: 'end abuse, exploitation, trafficking and all forms of violence against and torture of children'. As a way forward, the WHO's national recommendations call for countries to prioritise the collection of data on violence-related indicators to serve data-driven national action plans to prevent and respond to violence against children (WHO, 2020a).

In addition to positioning data collection on violence against children as a precondition to effective response and prevention measures, the international community has emphasised the importance of placing children at the heart of these research efforts, such as the UN Convention on the Rights of the Child (UNCRC) Article 44 (UN, 1989), UN study on violence (Pinheiro, 2006), and UN Sustainable Development Goals (UN, 2015), and suggested including children in research on violence 'through their ethical, inclusive and meaningful participation in evidence-based initiatives' (WHO, 2020a, p. 80).

Yet to date, the scientific investigation of children's reality of different forms of maltreatment is still marked by the streetlight effect – i.e. we seek the truth under the light, where the process of seeking is easy. We persistently ask parents and professionals in different roles about what forms of violence children experience and what help children and survivors of violence need, rather than looking where the truth is: children and survivors.

This book provides significant knowledge, based on strong evidence, embedded in the European context about participatory research on child maltreatment and violence with children and adult survivors. Together, the chapters of this book generate a colourful mosaic of contexts, theories and methods relating to children's and adult survivors' participation in research about their adverse experiences. It is expected to enrich the ongoing debates about ethical concerns, challenges and benefits of participatory research in the field of child maltreatment and violence and point to further directions to achieve progress.

Children's Participation in Society

According to the UNCRC (UN, 1989), children are both deserving and capable of participating in decisions concerning their life. Accordingly, children's participation is a process by which children express directly, individually or in a community, their opinions and decisions on matters that concern them according to their age and maturity (UN, 1989). Participation involves empowering children by considering them active agents and allowing them decision-making power that is usually preserved for adults (Shier, 2001; Sinclair, 2004; UNICEF, 2019). It is an interactional process in which children continuously engage with others, mostly adults, to achieve shared goals in a way that promotes mutual respect and dignity (Casas et al., 2008; Chawla, 2001). Such forms of participatory interactions are opportunities for children to construct meaning, share decisions and play a useful role in their community (Casas et al., 2008; Chawla, 2001).

A well-established conceptualisation of participation views it as a multidimensional construct with different degrees (Hart, 1992; Shier, 2001). Most notable is Hart's (1992) ladder of participation, which describes eight levels of children's participation, starting with the three non-participatory levels at the bottom, i.e. manipulation, decoration and tokenism, and moving upward to more meaningful participation through assigned but informed, consulted and informed, adult-initiated shared decisions with children, and child-initiated and directed to the final level: child-initiated shared decisions with adults (Hart, 1992). Subsequently, Shier's (2001) model of children's participation was designed to extend Hart's (1992) work and provide practical tool that can help professionals build an action plan to promote children's participation in different areas. Shier's (2001) tool presents five levels of participation: children being listened to, children supported in expressing their views, children's views being considered, children being involved in decision-making processes and, finally, children sharing power and responsibility for decision-making. In addition, each level can be evaluated by the degree of commitment to children's empowerment via openings, opportunities and obligations by which the participation becomes built into the system. Together, Shier's (2001) model provides an ordered sequence of 15 questions that can help professionals decide on the level of commitment to participation and the next steps to achieve greater participation.

Children's Participation in Research

To fully understand children's experiences, they must be involved in research (Greene & Hill, 2005). To achieve this scope, the scientific community must create participatory spaces and provide support and guidance to children (Smith & Bjerke, 2009). Valuing different levels of children's participation, this book considers that good practices of children's participation in research happen when research is done with children, rather than on or about children (Smart et al., 2001). Doing research with children is about more than ticking a box or reinforcing the opinions and views of adults; it is also about including them in different stages of the research process and making sure their opinions and collaboration are included in decision-making. Children may take roles as research advisers, data collectors, co-researchers or lead researchers (Cuevas-Parra, 2020).

Under the influence of the sociology of childhood, traditional research methods have been updated and included in the new paradigm of participatory research, by which children are invited to take part independently or in cooperation with adult researchers in different phases of the research: identifying and phrasing the research questions, planning the research instruments, testing the instruments, collecting data from other children and stakeholders, drawing conclusions and recommendations, disseminating the results of the research and planning to act to address the problems revealed by the research (Fargas-Malet et al., 2010; Larkin et al., 2014; Larkins, 2022). Involving children in roles that recognise their contribution to the accumulation of knowledge is a recognition of their value and capabilities. Therefore, researchers who want to make sure that children's participation is real need to focus on establishing a trusting and comfortable situation to help children get involved in the research process (Barriage, 2021).

In this book, children's and adult survivors' participation in research is defined as any research that entails a degree of collaboration between those undertaking the research and those who are typically the focus of the research (Pain, 2004).

Participation of Children and Survivors in Research on Maltreatment

From early ages, children directly or indirectly experience some forms of violence – affecting themselves, their family members, their peers or other people in their surrounding – and develop knowledge about it, which elicits some forms of behaviour and is embedded in their knowledge about self and the context of their lives.

The global commitment reinforced by the UNCRC (UN, 1989) to guarantee children's right to protection from maltreatment (Article 19) and right to participate in decisions about their life (Article 12) demands that researchers conceptualise new research paradigms that allow children to participate as experts informants on their victimisation experiences and as agents of knowledge construction who can contribute to the design, application and evaluation of research and dissemination of evidence-based knowledge.

The issue of participatory research with child victims has generated ongoing debates (Bovarnick et al., 2018; Kiili & Moilanen, 2019). It involves arguments rooted in the sociology of childhood, which recognises children as rights-bearing agents capable of reflecting on the realities of their lives and proposing solutions, alongside claims that children are less capable than adults regarding recalling details of victimisation, exaggerating, avoiding or imagining elements of the experienced events, or being retraumatised by recalling them (Bovarnick et al., 2018; Kiili & Moilanen, 2019; Sammons et al., 2016).

Expressing opinions about maltreatment might be difficult, especially for children who experienced violence because it involves contradictory emotions and risks or seems a betrayal of a person towards whom they feel ambivalent, both loving and being angry at them. Their capability to express themselves is often hindered by feeling powerless and dependent. Their agency might diminish, being influenced by the context of authoritarian and patriarchal norms and values, lack of resources and support, conflictual and abusive or neglectful parenting, or marginalisation and discrimination in their communities (Blanchet-Cohen, 2009). Therefore, researchers should contemplate what kind of methods they design and how they mobilise children's agency to get their meaningful cooperation in researching different aspects of violence that affect them (Jamieson et al., 2021).

This Book

This book is dedicated to sharing theoretical concepts, ethical considerations and research methods critical to collaborating in research with children and survivors of maltreatment and violence to reveal their authentic experiences. It is designed to purposefully address the challenges discussed in the literature about involving children and adult survivors in research about maltreatment so to contribute to the development of effective and ethical participatory research practice.

The book integrates theoretical and empirical knowledge developed by European scholars that have as a common focal topic the participation in research of children and survivors of violence that covers different forms of child abuse and neglect in the family, school violence, abandonment, institutionalisation, violence in deprived communities, exposure to life as a refugee and being left behind by labour-migrant parents.

The authors of the book are members of a pan-European network, Euro-CAN on Multisectoral Responses to Child Abuse and Neglect in Europe: Incidence and Trends (Euro-CAN), supported by the European Cooperation on Science Technology (COST Action 19106). The authors gather in a designated working group aimed to promote children's participation in research on violence in any of the many forms it affects children's lives in their families, institutions or communities where they live to help them live a better life. The authors represent varied disciplinary backgrounds, including education, psychology, paediatrics and social work. They are academic researchers, professionals in medical or social services and activists in civic associations of children and survivors of violence.

In sum, this book offers a comprehensive picture of how the concepts of child agency and victims' right to express their opinions on the violence affecting them can be fruitfully applied, using sound research methodologies drawn from different disciplines and developed by a range of professions.

Overview of Sections and Chapters of This Book

This book features 16 chapters organised in three sections.

Section 1

Section 1 establishes the overall grounding of participatory research with children on maltreatment experiences by touching on theoretical, methodological, ethical and contextual aspects. The first chapter is dedicated to theoretically debating the main concepts developed in the framework of childhood studies: children's participation rights, children's agency, and the views of adultism and childism. Chapter 2 reviews existing literature on participatory research with children and examines such research projects as those conducted by the EURO-CAN network, aiming to present the key features of participatory research with children.

Chapters 2, 3 and 5 paint comprehensive pictures about the cultural and social factors and formal policies and procedures that promote or hinder children's participation in research on violence. Chapter 3 discusses the main principles that guide child participation in research from the point of view of children's rights, how data should be protected and ethical considerations, including topics such as parental consent requirements and the consequences on the right of children to be heard.

Chapter 4 is an analysis of the evolution of different ethical approaches, mainly regarding the concepts of children's gatekeeping: What are the consequences of asking parents or care personnel for informed consent when studying children's experiences of family or institutional violence? The theoretical concepts introduced in this section are returned to and applied in the subsequent chapters of the book, through their critical examination and reflection on research involving children on maltreatment. Chapter 5 deals with cultural factors affecting the participation of children victims of child abuse and neglect in research, analysing the example of Turkey, with its collectivist culture.

Section 2

Section 2 presents a diversity of approaches useful to promote the participation of children of different ages and in different life contexts (Chapters 6–12). To enhance the practical value of knowledge, the book presents pioneering examples of effective participatory research initiatives with children from Sweden, Spain, Portugal, Iceland, Hungary and Romania as contributions to the discourse on child maltreatment. It demonstrates that despite the barriers imposed by extensive data protection regulations and caregivers taking advantage of their rights to act as gatekeepers, participatory procedures in research planning, data collection and the interpretation of results are beneficial in establishing a more reliable understanding of children's reality struggling to survive violence, discrimination and neglect.

This section includes chapters that explore the experiences of adult survivors of childhood abuse, long-term consequences of violence, and survivors' views on the support and the treatment they received from professionals. Readers will learn about what enhances healthy survival strategies and how professionals can better engage in child-centred supportive approaches, serving children's interests better. The section reflects on varied methodological approaches to participatory research, covering a large range of age groups and research typologies.

Readers will have the opportunity to understand how interviewing children and youth in foster care in Spain became a relevant participatory tool (Chapter 6). In Chapter 7, authors from Sweden present how their research centre (Barnafrid) involves children with refugee backgrounds in research and development activities. They describe the Barnafrid methodology, which can become a working model to understand the experiences and needs for safety of refugee children, in the communities they live in. Chapter 8 outlines the contribution of Hungarian foster kids for collecting young people's views on everyday life topics, and then develop digital tools considering the children's opinions and needs.

Details on innovative community work with young people expressing their feelings through artistic means are revealed by authors from Iceland in Chapter 9. Children's capacity to become co-creators of research methods is demonstrated by Romanian researchers working on the topic of children left behind in transnational families by parents migrating for work (Chapter 10). Portuguese colleagues discuss the opportunities put in place by participatory action research with children affected by community deprivation (Chapter 11). Examples of how Sweden promotes children's inclusion in research on violence and how children's voices have been articulated in different public enquiries that involve multiple societal sectors such as social welfare services and health care can be seen in Chapter 12.

Section 3

Section 3 approaches research on childhood maltreatment from the perspective of adult survivors of violence, remaining in the framework of participatory research. It presents how research with adult survivors of violence enhances child-centred participatory practices by building on adult survivors' retrospective accounts (Chapters 13–16).

This section discusses different ways to conceptualise survivors' contributions to knowledge accumulation on childhood maltreatment. Chapter 13 analyses models of working with mental health adult patients to capture their retrospective accounts of childhood maltreatment and Chapter 10 presents a contribution from Denmark. Chapters 14 and 15 (both from Germany) discuss the functioning of adult survivors of childhood violence in research projects. This is seen as differing in the degree of participation, inclusion and instrumentalisation. The roles attributed to adult survivors also vary depending on how their ways of expression are perceived; the adopted methods, like empowerment; or the use of creative practices with a therapeutic function (Chapter 14).

Childhood sexual abuse (CSA) survivors often reject research designs that ask them to passively respond to surveys. The authors of Chapter 14 explore why working with artists and art to capture sexual abuse is an approach that allows more freedom of expression and opens new communication dimensions for survivors of sexual abuse. Chapter 15 presents the approach of an association of survivors aiming for agentic participation in research. Their method encourages survivors of violence to participate in all phases of the research process in a way that may empower participants. Chapter 16 explores how researchers can give voice to the survivors of institutional abuse in Italy and other countries and how their contribution can be capitalised by raising community awareness of system violence with help from the survivors.

Recommendations

This book demonstrated that children can and are generally willing to voice their experiences of child abuse, neglect, abandonment and other forms of violence if they understand the meaning of the research, and are given the skills and support to express themselves and feel safe. It also suggests several steps to advance the inclusion of children in research so that it could more effectively serve the universal goal of eliminating violence against children.

First, while children are typically mostly involved in the stage of conducting the study, we recommend that children should play a leading role in all phases of the research from the early stages of planning the research to the final stages of disseminating its results. This will allow a rebalancing of the power between adult researchers and child participants throughout the whole research process.

Engaging children in decisions on the research questions could advance empirical investigation that addresses problems that are important to children from their perspective. Studying issues that children prioritise as significant could benefit the development of more pertinent and appropriate solutions and interventions so that the systems built to protect children will meet their mission.

Also, the inclusion of children in designing the research methodology could promote the establishment of facilitating conditions for data collection and maximise the potential for children's participation. Children's input can stimulate innovative child-appropriate data collection strategies which follow the natural ways children interact with their environment.

In the long term, taking a children-led approach to framing the research may facilitate children's narratives on violence as well as those groups that are typically less involved in research such as young children or children with disabilities.

It is also suggested that greater attention should be given to the inclusion of children in disseminating research results. Scientific evidence presented through this book makes a case for the benefits of providing child decision-making power and control over approaches to distributing research findings. Through research, children develop the skills and agency to advocate and act for changes in their environments including families, institutions and communities.

Given the vulnerability of children in general and victims of maltreatment and violence in particular, it is recommended that research be built on strong ethical grounds. It is important to ensure children's participation or non-participation is a free choice and not a product of adult manipulation or gatekeepers exercising their power. In some cases, this may involve waiving parental consent. It is also recommended to put in place clear institutional safeguarding procedures, for example, repeatedly and deliberately presenting the option to stop participation at any time they want or train children to express their needs to the field researchers so support could be immediately provided.

When we consider research with CSA survivors, there is a similar situation with the children's case: often the studied population is only a passive agent, and the researcher decides the research question, design, methodology and procedure. The lack of participatory research with CSA survivors about child maltreatment is an indicator of how much more information on how to do so is needed.

The recommendations are in three directions. Firstly, it is important to conduct more participatory research with adult CSA survivors to prove their benefits when they participate in research. The lack of knowledge on the level of benefits for the studied population should not be an impediment to not conduct such participatory research. Hence, the opposite. Other populations in vulnerable situations have been included in research since a long time ago, and all the studies point out how useful it is for the participants and how rich the research is when they participate. Once the evidence on the benefits of participating is established, it will be a good piece of information to find and encourage adult CSA survivors to participate in research about child maltreatment.

Secondly, as mentioned before, some ethical issues should be taken into account. The researchers must protect adult CSA survivors when participating in research, avoiding retraumatisation and considering all the risks taken.

And thirdly, the main recommendation for research with adult survivors of violence and its practical implications taking into account their opinions regarding the key aspects of how to involve children who sadly are victims of child maltreatment. In retrospect, adults can have important inputs for research and policies on how to approach, involve, motivate, help and empower children who lived similar experiences to them. There are no better experts than the children and survivors: we cannot overlook their voices and decisions.

The last recommendation would be to consider cultural factors when doing research on child maltreatment with children and survivors. In some cases, there is a genuine resistance against considering children good enough to participate in research as main characters. This resistance is rooted in familial, institutional and societal traditions. These cultural values which hinder research on the topic of violence against children are the same values that maintain the violence itself.

Therefore, we need guides for researchers and experts to help identify cultural barriers and find solutions to overcome them. Identifying these values and finding ways that allow children's voices to be heard in societies with traditional and patriarchal norms can bring forward the values of children's right to protection and self-expression to the attention of the communities.

Finally, a word of caution is required. Researchers should not take the potential benefits of children's participation for granted. Rather children's feedback and reflections about their participation experience should be deliberately and explicitly sought, particularly when exploring difficult life experiences such as maltreatment. To advance meaningful, ethical and effective research with children, more evidence-based knowledge is required about the experience of participation in research from children's perspectives.

Conclusion

We hope that the authors of these chapters succeed in sparking readers' interest and motivate them to take inspiration from the research examples presented in these chapters. We invite our readers to reflect on the challenges of involving children and adult survivors of maltreatment in research on their harmful experiences of abuse and neglect and the consequences of such adverse experiences. We hope that the book also highlights effectively the advantages and positive effects that participation as a human right and as a valued endeavour of scientific knowledge accumulation can bring to the community of helping professions.

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Chapter 1

Theoretical Grounding on Children's Participation in Research on Maltreatment

Fiona Morrison

Abstract

Drawing on key concepts from childhood studies, this chapter provides a theoretical grounding for children's participation rights in research on maltreatment. The chapter discusses the sociology of childhood, tracing how it brought a focus to children's participation in research, and introduces the concepts of adultism and childism to help critique children's participation in research on maltreatment. The chapter is framed by a familiar debate on tensions between children's right to participate and their right to protection. It explores the relevance of these debates for research on child maltreatment. Through its discussion, the chapter explores key issues that have traditionally led to children being kept out of research on child maltreatment. It argues that children's participation is key to advancing knowledge on child maltreatment and fundamentally a way to uphold children's human rights. The concepts introduced in this chapter are threaded and explored throughout the subsequent chapters of the book, in their examination and reflections on children's participation in research on maltreatment.

Keywords: Children's participation; sociology of childhood; childism; adultism; children's rights framework; participatory research

Introduction

Children's participation in research is important to improving and developing knowledge and the evidence base on child maltreatment. It provides a means to gain critical insights on maltreatment from children – the group most affected and

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marginalised by child maltreatment. It allows us to answer critical questions like: How do children experience and understand maltreatment? What impact does maltreatment have on their lives? How might law, policy and practice be improved to better support children and ameliorate the impacts of maltreatment?

Without children's participation, knowledge on child maltreatment is at risk of being partial and efforts to protect children could be ill considered and ineffective. As well as contributing to knowledge, children's participation is key to implementing children's human rights. It is a way to facilitate children's representation, to ensure their interests and views are heard, taken seriously, and prioritised in policy decisions about child maltreatment (e.g. Kosher & Ben-Arieh, 2020). It also has the potential to be transformative for children, both individually and collectively. It can be empowering and support children's activism and action in addressing child maltreatment (e.g. Houghton, 2015; Tisdall & Cuevas-Parra, 2020, 2022).

However, children's participation in research – especially research on child maltreatment – is complex and contested. Adults may be concerned about children's vulnerabilities, including the extent to which they may manifest and can be reconciled in the research process. These concerns often surface in questions around children's capacity to participate, whether children have adequate levels of knowledge or expertise to participate and the potential negative consequences of participation for children. This can be especially acute in research that invites children to share or draw on their experience of maltreatment. Although participation in this area is complex, a focus on protectionism at the expense of children's participation risks denying the most marginalised children the opportunity to be heard, the effects of empowerment and achieving positive change at an individual and collective level that can emanate from participating in research.

Drawing on key concepts from childhood studies, this chapter provides a theoretical grounding for children's participation in research on maltreatment. The chapter discusses the sociology of childhood, tracing how it has brought a focus to children's participation in research and introduces the concepts of adultism and childism. It explores children's human rights, elaborating on children's participation rights. Through its discussion, the chapter explores key issues – children's capacity, knowledge and expertise and the impact of participation on children – that have traditionally meant children are excluded from research on child maltreatment. The theoretical concepts introduced in this chapter are threaded and explored throughout the subsequent chapters of the book, in their examination and reflections on children's participation in research on maltreatment.

Theoretical Devices for Thinking About Children's Participation in Research on Child Maltreatment

This section introduces key theories from childhood studies. They are used to unsettle assumptions about children and childhood. This discussion highlights issues like capacity, questions about children's knowledge and concern about their vulnerabilities that could limit children's participation in research on child maltreatment.

Sociology of Childhood

The sociology of childhood, a key theoretical strand of childhood studies, emerged in response to and as a critique of dominant child development and family studies paradigms about children and childhood. Taking insights, particularly from sociology and social anthropology, researchers argued that childhood was socially constructed (Mayall, 2002). As such, childhood is not a stable concept; rather, it is influenced by particular ways of thinking about children and childhood, cultural norms and academic disciplines. Broadly speaking, in the Global North, proponents of the sociology of childhood have argued that the lenses of child development and family studies had been overly dominant and wrongly characterised children as incomplete and wholly dependent on adults. These characterisations viewed children as 'adults in waiting', with a resulting policy and research focus on children's future productivity in adulthood. Childhood was as a stage to be completed before the ultimate goal of adulthood achieved. As Qvortrup (1994) notably stated, children are constructed as 'human becomings', not as 'human beings':

> Adulthood is regarded as the goal and end-point of individual development or perhaps even the very meaning of a person's childhood. They are however revealing for the maybe unintended message, which seems to indicate that children are not members or at least not integrated members of society. This attitude, while perceiving childhood as a moratorium and a preparatory phase, thus confirms postulates about children as "naturally" incompetent and incapable. (p. 2)

Qvortrup (1994) questioned the status afforded to children in society, arguing that children are not treated as full 'members', or at least not 'integrated members'. He raised a concern that children's competence and capacity were in question, or rather that children are assumed lack of competence and capacity. Proponents of the sociology of childhood assert that rather than understanding childhood as a preparatory phase as noted by Qvortrup, it should be understood as a social category, much like other categories of race, gender, and disability. Like these other social categories, childhood is worth considering in its own right and should be understood to be a social construction and socially constructed. Prout and James (1990) explained this effectively: 'A child's immaturity is a biological fact: but how this immaturity is understood and how it is made meaningful is a fact of culture' (p. 7).

So, although children are biologically immature, how society and adults respond and ascribe meaning to this is a cultural issue. Embracing the sociology of childhood calls for a paradigm shift – from viewing children through the prism of child development norms to viewing children and childhood as socially constructed and deserving of greater respect. The sociology of childhood marked a departure from a traditional view of children as wholly passive and dependent on the family (Mayall, 2002; Qvortrup, 1994). It called for respect of children in the present, not in terms of their future contribution as adults. It demanded greater respect for and acknowledgement of children as social actors and holders of rights. This all has implications for how we think about and involve children in research. James and Prout (1990) outlined a new paradigm for understanding and researching children and childhood. Several points are especially salient for our consideration here on research on child maltreatment:

- Childhood is a variable of social analysis.
- Children's social relationships and cultures are worthy of study in their own right.
- Children are and must be seen as active in the construction and determination of their social lives, the lives of those around them and the society in which they live.

This paradigm of childhood was and continues to be part of challenging and reconstructing how children and childhood are conceptualised. It aims to unsettle dominant constructions of childhood in the Global North, where children were characterised as being vulnerable, dependent, innocent and incompetent. Instead, it calls for recognition of children's expressions of agency and rights. Adopting a sociology of childhood lens has profound implications for children's participation in research on child maltreatment. It encourages us to reject the assumption that children are wholly vulnerable and dependent on adults. Instead, it encourages a view of children as having contributions to make to research and rights that must be fulfilled. Research strategies that privilege and emphasise adult perspectives and responsibilities are called into question. A traditional orthodoxy of research about children (and research on child maltreatment), where the views and experiences of children have been filtered through the accounts of adults, must be overhauled – adults cannot be seen to be proxies for children. Rather, research on and resulting responses to child maltreatment must recognise children as individuals in their own right – individuals with integrity, individuals with status and individuals who should be able to choose whether and how to participate in research that affects their lives. Thus, through the sociology of childhood, the child becomes a, if not the, central actor in research (Christensen & James, 2008), including in research on child maltreatment.

More radical social movement ideas of oppression and discrimination are beginning to be articulated in childhood studies through the concepts of adultism and childism. These constructs recognise that unequal power relations between adults and children create attitudes, systems and institutions that privilege adult norms and subordinate children (see Alderson, 2020; Sundhall, 2017; Wall, 2022). In research on child maltreatment, this may manifest in excluding children from research due to adults' concerns about their capacity, knowledge or vulnerability, rather than perceiving children as key to research and their views and experiences as relevant to understanding and addressing child maltreatment. Such attitudes may not be maliciously intended, and researchers working in these domains may be acting with the best of intentions. However, there is danger that privileging these concerns and perceptions creates systematic disadvantage, discrimination against children and oppression of children as a group. In adopting a childism lens, we see that children's participation is necessary – as is the reimagining research to be inclusive of children.

Children's Human Rights

In parallel with the sociology of childhood has been the growth of the children's rights movement (Mayall, 2015). The United Nations Convention on the Rights of the Child (UNCRC) was adopted by the UN Assembly in 1989 and has been vital in advancing children's human rights across the globe. Countries may ratify the UNCRC and then become obliged to make the rights that it enumerates for children a reality. Although the word 'participation' does not appear in the text of the UNCRC, it is the term used in the children's rights field to encompass the requirements of Article 12 of the UNCRC and other associated rights. As well as being the most cited participation right of the convention, Article 12 is also recognised as one of the general principles of the UNCRC by the United Nations Committee on the Rights of the Child (1991),[1] thus highlighting its importance and standing across the convention.

Article 12 of the UNCRC ensures children the right to participate in all decisions that affect their lives. It requires that:

(1) States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
(2) For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Articles 13, 14, 15 and 17 further outline children's related participation rights regarding freedom of expression; freedom of thought, conscience, and religion; freedom of association and access to information.

The UN Committee on the Rights of the Child provides further and extensive guidance through its general comments on the interpretation and the implementation of the UNCRC. As authoritative interpretations of the UNCRC, the general comments provide a detailed framework by which we can consider

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[1] The other three general principles are the right to non-discrimination (Article 2); the best interests of the child (Article 3) and the right to life, survival, and development (Article 6).

implementing children's participation rights in a research context. The general comment on Article 12 (United Nations Committee on the Rights of the Child, 2009) elaborates on the implementation of children's participation rights. It implies that children's views should have influence on decision-making, encompassing decisions made about an individual child and collective decisions about children. Therefore, interpreting Article 12 demands an expansive understanding of children's participation, from individual decisions about children's lives to their broader participation in the development of policy and research on child maltreatment. The general comment on Article 12 defines participation as follows:

> This term has evolved and is now widely used to describe ongoing processes, which include information-sharing and dialog between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes. (p. 3)

In a research context, children have the right to participate in research that affects their lives, including on child maltreatment. From a rights perspective, participation is more than data collection; it extends beyond collecting children's views or data about children. Rather, participation is understood to be an ongoing process that is underpinned by and requiring of respect between researchers and children. Thus, it requires researchers to provide feedback to children on the impact of their involvement in research, from findings to research impact.

The sociology of childhood and children's human rights are key theoretical ways to consider children's participation in research on child maltreatment. At their core, they provide a challenge regarding how research and researchers perceive children and childhood. They invite us to reconsider issues like children's capacity, questions about children's knowledge and concern about their vulnerabilities. The task for researchers, therefore, is to ensure that such concerns are considered critically and not simply used as reasons to limit or even exclude children from research on maltreatment.

Defining and Implementing Children's Participation in Research

The phrase 'children's participation in research' is used across the literature to refer to the varying ways children may be involved in research. It perhaps risks being a somewhat elastic phrase, encompassing children as participants of research, researchers and advisors to research and the other ways that children may influence research agendas and processes. Montreuil et al. (2021) highlighted important distinctions between participatory data collection methods with children and children's broader participation in decisions about research. Participatory methods are the ways in which researchers engage with children to collect data about them, whereas children's broader participation refers to how they are involved in and exert influence over research. This may include but is not limited to defining research questions for a study, designing its methods and ethical approach, carrying out data collection, engaging in data interpretation and analysis, and making decisions about and leading research dissemination activities.

A rich seam of scholarship conceptualises the implementation of children's participation in policy and practice. Although not all explicitly about research, it provides important and useful considerations for those who wish to advance children's participation in research on child maltreatment.

Hart's (1992) ladder of participation is arguably the best-known model for child participation. Based on Arnstein's (1969) ladder of citizen participation, Hart's model has eight rungs: (a) manipulation; (b) decoration; (c) tokenism; (d) young people assigned but informed; (e) young people consulted and informed; (f) adult-led with shared decisions; (g) youth-led and directed; and (h) youth-led with shared decisions with adults. Shier's (2001) pathways to participation model builds on Hart's work, incorporating an additional dimension to help adults consider how they facilitate or limit children's participation.

These uncover key concerns that remain for researchers and practitioners engaging in research on child maltreatment. They encourage us to explore the status of children and consider how power is distributed between adults and children in the research process. Key questions that arise include: How do we ensure children's participation is a free choice and not a product of adult manipulation? To what extent is children's participation in our research tokenistic? Do children really have influence over the research, or is their involvement a strategic resource for our research? Is it preferable or even possible for power to be shared or handed over to children during the research process? What might be the implications of doing this, especially in areas like child maltreatment? Answers to these questions are not straightforward and may well rely on the particularities of research projects, the contexts in which they take place and the children they seek to involve. Rather, it is the reflexive application of concepts from Hart's and Sheir's work – making visible and interrogating the status, power and influence that children have in research (and why) to provide a means for researchers to consider children's participation in their research and how it may be advanced.

Lundy's (2007) model on children's participation identifies four key elements for children's participation in decision-making to be effective and compliant with their participation rights. First is space: Children must be guaranteed a safe space where they can feel free to discuss, share, debate and decide what they want to say and how to say it, and plan their actions. Second is voice: Children and young people must receive the support they need to speak out and express their views. Third is influence: Children's and young people's views must be taken seriously and acted upon. The fourth element is the audience: Children's and young people's views must be communicated to someone who has responsibility to listen and act.

This model not only elucidates the conditions necessary for children to express their views but also underscores the importance of children's involvement in the actions that follow. This is underpinned by a conceptualisation of children as experts and a key to developing solutions and delivering change. Thus, we see how it challenges ideas about children's capacity and their competence. As with Hart's and Sheir's work, Lundy's model offers a way for researchers to consider the extent to which their research design and practices support children's participation. Does it begin and end with Lundy's element of space through participatory methods? Or does it extend to influence and audience, providing opportunities for research to be transformative for children and support their activism and action in addressing child maltreatment? Such decisions must consider not only the aims of the research but also how participation is experienced by children. Does it feel ethical? Is their participation meaningful or is it tokenistic? (e.g. Gallacher & Gallagher, 2008; Groundwater-Smith et al., 2014). Bradbury-Jones et al. (2018) argued that although participatory research with all children is complex – practically, methodologically and ethically – it offers a way to address some of the issues that are especially potent for research with vulnerable and marginalised children, like those who have experienced maltreatment. Moreover, participatory research has the potential to find ways to value and bring to the fore the experiences and views of people who otherwise might be excluded from research owing to being constructed as 'too vulnerable' or having needs that are too complex to be accommodated in more 'traditional' research.

The literature discussed here seeks to challenge and upend unequal power relationships – relationships between adults and children and between researchers and research participants. In doing so, it gives insight on how concepts from the sociology of childhood and children's rights may be applied to research on child maltreatment.

Challenges to Children's Participation in Research on Maltreatment

Familiar debates on children's participation more generally may be traced through the children's rights literature and tensions between supporting children's participation and protecting their best interests (Archard, 2004; Collins, 2017; Marshall, 1997; McMellon & Tisdall, 2020). These tensions are held, in part, by the different conceptualisations of children and childhood.

Broadly speaking, underpinning the ideas of child participation is the view that children are experts, accompanied by the aim of supporting children's involvement and extending their agency and influence. In a research context, this translates not only to engaging children in data collection but also to adult researchers sharing or handing over power regarding the research to children. In contrast, underpinning the ideas of protecting children's best interests is the view that children are vulnerable and incapable, with the accompanying aim of protecting children. In a research context, this may manifest in limiting or excluding children's participation in research to protect them. Although participation in this context is undoubtedly complex, a focus on protectionism, at the expense of participation, risks denying the most marginalised children the effects of empowerment and achieving positive change at an individual and collective level. It is tempting, therefore, to choose one over the other – to prioritise research for individual agency over responsibility for safety.

Such opposing conceptualisations of children, as vulnerable or agentic, risk decoupling one from the other, when in fact it is the relationship between them that is important. The right to participate in research about maltreatment should be understood in relation to the right to be protected from harm. This means that in research with children, including research on child maltreatment, researchers need to make space for and attend to ideas of children's agency and vulnerabilities. In other words, research should recognise and support children's expertise and agency and work in ways to further protect and maximise children's best interests. By holding these conceptualisations of children in tension, the practical, methodological and ethical necessities and complexities of children's participation in research on child maltreatment emerge. Children's right to protection is deeply entwined in implementing children's right to participate in research on child maltreatment.

However, in research, protective rights might be used to exclude children from research. For example, they could be used to position children as being 'too vulnerable' to participate in research, leading to the restriction or circumvention of their participation rights (see Archard, 2004; Hill & Tisdall, 1997; James et al., 1998; Wyness, 2012). Such paternalistic responses are put forward as protective measures that limit opportunities for adult pressure and manipulation of vulnerable children in research and a means to limit any allied distress. This could prevent children from sharing their experiences and needs and limit their opportunity to influence policy and practice. Fundamentally, it risks producing an epistemic injustice (Fricker, 2007) that ignores children's accounts of their lives. It is a harm in its own right that further risks excluding children from policy and practice decisions that affect their lives (see Morrison et al., 2020).

This brings us back to the tension that lies in protecting a child's best interests and recognising a child's participation rights. The United Nations Committee on the Rights of the Child (2009, 2013) has wrestled with articulations between a child's best interests and participation rights, with the goal of ensuring neither are subsumed. Children's participation rights should be recognised on their own and in conjunction with children's welfare. Indeed, these rights are complementary and interrelated. Protective rights can be used to galvanise action on implementing children's participation rights in research on maltreatment. Similarly, children's participation rights offer a way to uphold their protective rights. In attending to both children's protective and participative rights, new ways to involve children in research on child maltreatment can emerge – ones that are emancipatory and empowering and that prioritise and advance the interests of children.

A Way Forward? Adopting a Rights Approach to Children's Participation in Research on Child Maltreatment

Returning to the UN Committee on the Rights of the Child's (2009) general comment on Article 12, we find a useful and expansive interpretation of how to implement children's participation rights. This approach seeks to maximise the potential for children's participation, including children with difficult experiences like child maltreatment. Through it, we can begin to see that in adopting a children's rights lens, the question becomes not if children should participate but rather how their participation may be best facilitated. Its interpretations and ensuing implications for research are summarised in Table 1.1. This offers a way for researchers to adopt a rights approach to children's participation in research on maltreatment, attending to both children's protective and participative rights.

Table 1.1. Using a Rights Lens to Implement Children's Participation in Research.

Questions About Children's Participation and Research	Provisions Made by the CRC General Comment on Article 12	Ensuing Implications for Implementing Children's Participation Rights in Research
Do children have the capacity to participate in research?	A child should be presumed to have the capacity to form their own view: 'It is not up to the child to first prove his or her capacity' (para. 20).	Children should be presumed capable to form views and capable of participation in research – the onus is on researchers to design research that supports children's participation.
What weight should children's views have in and about research?	'Being given due weight in accordance with the age and maturity of the child' requires views to be considered seriously (para. 28).	Children's views should be given weight and taken seriously. The weight given to children's views will depend on their age and maturity.
At what age can children participate?	There is no age limit on the right of the child to express their views (para. 21).	Age should not be a determinative factor in decisions about children's participation in research.

Table 1.1. *(Continued)*

Questions About Children's Participation and Research	**Provisions Made by the CRC General Comment on Article 12**	**Ensuing Implications for Implementing Children's Participation Rights in Research**
Do children know enough to be able to participate?	A child need not have comprehensive knowledge to be considered capable (para. 21).	Children's knowledge (complete or otherwise) should not be a barrier to their participation in research.
Are some children too vulnerable to participate?	Children experiencing difficulties must have opportunities to express their views (para. 21).	Children with experience of maltreatment should have the opportunity to participate in research about maltreatment.
	State parties must be aware of the 'potential negative consequences of an inconsiderate practice of this right' and ensure the 'full protection of the child' (para. 21).	Children's participation must be carefully thought through. Participation should not have adverse consequences for children.
	A child should not be 'interviewed more often than necessary, in particular when harmful events are explored' (para. 24).	Care and attention are required when researching maltreatment with children. Participation should not involve the repeated exploration of harmful events.
What do children need to be able to consent to participation?	Information is a precondition to a child's 'clarified decisions', both in terms of (a) the matters, options, and possible decision to be taken and their consequences and (b) the conditions under which the child will be asked to express their views (para. 25).	Researchers need to give children information about participation before children can consent to participate.

Table 1.1. *(Continued)*

Questions About Children's Participation and Research	Provisions Made by the CRC General Comment on Article 12	Ensuing Implications for Implementing Children's Participation Rights in Research
What happens after the research ends?	Feedback should be provided to the child on the outcome and how the child's views were considered (para. 45).	Researchers are responsible for reporting to children about the outcome of the research and how children's views were considered.

Conclusion

Children's right to participate in research that is about them is not necessarily at odds with their right to be protected from harm, even when that research is about the maltreatment of children. The sociology of childhood offers useful theoretical resources to provide a rationale for children's participation in research on child maltreatment, including children's rights, children's participation rights and important considerations for meeting these rights. Through discussion of these resources, the chapter has explored the importance and relevance of these concepts for research on child maltreatment, setting out some key dilemmas and challenges that emerge when conducting research with children and implementing their participation rights in this context. Subsequent chapters take up these dilemmas and challenges through various theoretical and methodological approaches and innovative solutions.

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Chapter 2

Children's Participation in Research on Violence Affecting Them: A European Overview

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Abstract

The objective of the chapter is to provide an integrative appraisal of recent participatory research projects with children on violence and maltreatment conducted by members of the COST Action CA 19106 working group on children's participation (WG3) and their colleagues to identify what is working well and what needs to change in future research. The evaluation of research examples clustered around four key questions: Why, when, how and how much do children participate in research? Data were collected using a unified tool designed to characterise participatory research, which was distributed among WG3 members. In addition, chapters of the current book were another source of data about participatory research. Overall, data on 19 studies involving 46,761 children were collected and analysed using Shier's matrix. Findings show that most studies ($n = 10$) engaged children as consultants to adults in data collection, whereas a few studies ($n = 5$) demonstrated a more children-led research approach. The analysis uncovered specific areas where more progress is required, including engaging children in decisions about the research topic, involving young children, utilising methods that are more natural and familiar to children, and gaining children's reflective accounts about their participation experience. The authors encourage scholars to publish their work to advance evidence-based knowledge and skills in participatory research with children about sensitive topics.

Participatory Research on Child Maltreatment with Children and Adult Survivors, 27–49
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Keywords: Research design; participatory methods; adult-led research approach; child-led research approach; Shier's matrix; violence

Introduction

Participatory research with children is a highly controversial issue in the scientific literature (Kiili & Moilanen, 2019; Liebenberg et al., 2020; Pavarini et al., 2019; Schelbe et al., 2015). Generally, children's participation in research is an ideological or rights-laden issue, depending on the social and cultural contexts, that in practice imposes particular logistical, methodological, and ethical considerations – for example, in relation to gaining access via gatekeepers, managing informed consent, ensuring freedom to decline or withdraw participation at any time, dealing with possible breach of confidentiality in high-risk situations and providing compensation (Carnevale, 2020; Lundy et al., 2011; Nigel, 2015; Schelbe et al., 2015). In addition, as demonstrated throughout this book, when aiming to empirically study children's realities of abuse, neglect and violence, the challenges and complexities of participatory research increase to a great extent (Bovarnick et al., 2018; Kiili & Moilanen, 2019). See Chapters 1 and 5 for discussions about influences of sociocultural factors on children's participation, Chapter 3 about data protection practices and Chapter 4 about ethical considerations.

Nonetheless, inclusion of children in research was shown to enhance the quality of empirical investigation and its outcomes – for example, by refining data collection tools and adding to the richness, relevance and credibility of research findings (Bovarnick et al., 2018; Pavarini et al., 2019). Evidence of the impact of participation on children is very scarce (Pavarini et al., 2019). Scholars have suggested that involvement in research can be beneficial for children as an opportunity to enhance confidence, resilience and agency; acquire new knowledge and skills; and offer a therapeutic quality in the context of violence victimisation (Bovarnick et al., 2018; Lundy et al., 2011).

Although children's involvement in social science and health research has grown markedly during the last few decades (Nigel, 2015) and especially in Europe (Schelbe et al., 2015), participation in research about violence and maltreatment is still insufficiently developed (Bovarnick et al., 2018).

The objective of the current chapter is to provide an integrative appraisal of recent participatory research projects with children on violence and maltreatment conducted by professionals and researchers, members of the COST Action CA 19106 working group on children's participation (WG3) and their colleagues to identify what is working well and what needs to change in future research. Outcomes of our analysis can direct future avenues of investigation and shed light on the skills and knowledge required to facilitate meaningful, ethical and effective participation of children in research in this field.

To advance progress, the evaluation of practice examples purposefully focused on recognised weak points or shortfalls of research with children in general that have been reported in the literature. The exploration of practice clustered around four key questions: Why, when, how and how much do children participate in research?

Why, When, How and How Much?

Starting with the issue of why children participate in research, this topic draws attention to research objectives and questions. Lundy and her colleagues (2011) argued that the actualisation of children's right to participate via engaging them in research should not undermine their right to have their best interest considered (United Nations, 1989, Article 3). This can be interpreted in this context as expectations that research outcomes will be beneficial for children – for example, by leading to improvements in their communities and services. By and large, participatory research with children focuses on problems identified by adults in children's environments such as schools, communities and services settings with the aim of generating effective solutions or services (Nigel, 2015). In other words, in general, the best interests of children, in most cases, arise from adults.

In terms of when children participate in research, this question has two distinctive dimensions: (a) the child's age and (b) the stage in the research process. In relation to children's age, evidence shows that children younger than eight years old are less involved in research than older children (Lundy et al., 2011). Although some researchers have argued that young children lack the competence and skills to engage in research, others posited that children's contribution to research is not age dependent but rather a factor of the child's life experiences, including in research processes, and how research is tailored to the child's developmental level and meets the child's supportive needs (Lundy et al., 2011; Schelbe et al., 2015).

Turning to the research process, in general, participation is not consistent along all research stages and is most common during data collection phases (Kiili & Moilanen, 2019). There is limited evidence of children being involved in decisions about research questions, study design, data analysis or interpretation processes, although their participation at these stages is essential to ensuring the findings reflect their realties in an accurate and insightful way (Kiili & Moilanen, 2019; Liebenberg et al., 2020; Lundy et al., 2011; Nigel, 2015). In addition, examples of children's involvement in research outcome dissemination and utilisation initiatives are also scarce (Carnevale, 2020; Kiili & Moilanen, 2019). Scholars have argued that children's engagement in data analysis and dissemination is essential if researchers are to meet their obligation to give children's views due weight (Liebenberg et al., 2020; Lundy et al., 2011).

The question of how children participate directs our attention to research methodology. Some researchers highlighted the advantages of using qualitative data collection techniques in gaining a meaningful, thorough and contextual understanding of children's life experiences and perspectives (Carnevale, 2020; Schelbe et al., 2015). In addition, Carnevale (2020) argued for using qualitative data collection approaches that emphasise the relational dimension of the interaction to promote trust, neutralise the power imbalance between adult researcher and child and follow the natural ways children engage and communicate with their environment. For example, researchers could use participant observation, informal interviews, art-based research and play (Carnevale, 2020).

Evidence shows a wide range of age-appropriate creative strategies to involve children in research as participants. For example, research with young children with limited or lack of literacy and numeracy skills could emphasise visual and kinaesthetic strategies such as drawing, storytelling, tours and photography (Kiili & Moilanen, 2019; Lundy et al., 2011), whereas research with young adults could involve the use of digital games and applications, text messages and social media (Kiili & Moilanen, 2019; Liebenberg et al., 2020; Pavarini et al., 2019). For more discussion about the utilisation of digital applications in research, see Chapter 8.

Finally, the question of how much children participate is directly linked to the discussion presented in the introduction chapter about the lack of a unified, agreed-upon definition of participatory practice (Kiili & Moilanen, 2019). As mentioned, the concept of participation is used in the literature to describe varied forms of children's engagement in research, ranging on a continuum from children being consulted on issues such as research design and tools, to child–researcher collaboration on different research tasks, to children coleading or independently leading the research process (Kiili & Moilanen, 2019; Lansdown & O'Kane, 2015; Shier, 2019). The lack of precision and clarity in the use of the concept of participation in research can be interpreted as a barrier to children's participation (Skauge et al., 2021).

Methods

Data Collection

Data collection for this chapter was not designed to meet standards of representativeness. Rather, we sought to provide an overall comprehensive reflection about current work by researchers and professionals, members of WG3 and their colleagues.

During our group's regular bimonthly online meetings in 2021, we asked colleagues to gather local examples of successful participatory research with children about violence and maltreatment. Members received a unified data collection tool drafted by the authors for this purpose to support documentation of detailed information. Seven group members used the tool to report on 12 studies carried out by them or their colleagues. In addition, we included in the data analysis studies presented in Section 2 of this book (see Chapters 6–12). All in all, data on 19 studies[1] were collected and analysed.

The key merit of such approach is the ability to collect data that goes beyond articles published in peer-reviewed journal, including grey literature such as research reports. Moreover, we could access data published in languages other than English that otherwise would have not been accessible in the international literature.

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[1] Studies included in the analysis are marked by asterisks in the reference list.

Data Analysis

For the analysis of data collected, we used an adaptation of Shier's (2019) matrix for analysing children's engagement in research processes. The tool was originally designed to help researchers explicitly consider children's involvement when initially planning and designing a study, yet it can also be used to evaluate research retrospectively (Shier, 2019). The tool breaks down the research process into nine distinctive stages or tasks related to framing, conducting and disseminating the study's results. Specific stages include generating the research question; designing the research and choosing methods; preparing research instruments; identifying and recruiting participants; collecting data; analysing the data and drawing conclusions; producing a report; disseminating the report and its findings; and advocating and mobilising to achieve policy impact. In relation to each stage, children's engagement is evaluated according to the level of decision-making power and control they employ – ranging from no involvement, to children being consulted by adult researchers, to children collaborating with adult researchers, to children directing and deciding on research processes for themselves, which is the highest level of exercising power and control. Through data analysis, each of the 19 studies was assessed according to the adopted matrix.

Results

The main characteristic of the 19 studies analysed are presented in Table 2.1.

As can be seen in the table, overall, 46,761 children were included in 19 studies about sensitive issues such as experiencing violence, maltreatment, discrimination, social deprivation, poverty and living in out-of-home placements. The earliest study reported on was conducted between 2010 and 2012, and the latest is still in progress. About half of the studies ($n = 9$) were recent, conducted from 2020 onward. Studies were conducted in Hungary ($n = 4$), Romania ($n = 2$), Portugal ($n = 2$), Spain ($n = 2$), Iceland ($n = 2$), Sweden ($n = 2$), Greece ($n = 1$) and Norway ($n = 1$). In addition, three studies were international research projects involving between three and nine European countries. The most common research settings were community institutions or facilities such as schools ($n = 7$) and culture and leisure facilities ($n = 4$). Some studies were conducted in child protective services or placement settings ($n = 6$), and two studies were conducted online.

Why Children Participate

Most studies ($n = 9$) explored children's exposure to violence of different types (e.g. cyberbullying) and settings (e.g. home, school, community), aiming at identifying the degree and features of the problem and possible solutions. Second, some studies ($n = 6$) were designed to evaluate the quality of child protection systems' support and care services and their ability to address children's service needs. In addition, a few studies ($n = 3$) investigated the experience of living in severely deprived environments or transnational families, and one study focused on the ethical dimension of participatory research.

Table 2.1. Summary of Studies Main Characteristics.

Author (Year), Country	Study Duration	Setting	Sample	Children's Key Vulnerability	Research Aim	Research Design
Árnadóttir and Einarsdóttir (2023), Iceland	2016–2017	Community art exhibition about the UNCRC	1,437 notes (wishes) by children aged 3–17 attending preschool and compulsory school and three children aged 16 or 17 years from Child Welfare Youth Council	Exposure to violence	Develop art-based means to promote children's discussion of violence and abuse	*Qualitative*: Children provided written comments (wishes) following participation in an exhibition. Wishes were hung on a 'wishing tree' or placed into a bird box inside the exhibition area
Árnadóttir and lsdóttir (2019), Iceland	2019	Library in a culture centre	11 children aged 7–12 years	Living in poverty (parents depend on income support)	Understanding the experiences of children living in poverty	*Qualitative*: Semistructured interviews including the use of drawings and pictures

Table 2.1. *(Continued)*

Author (Year), Country	**Study Duration**	**Setting**	**Sample**	**Children's Key Vulnerability**	**Research Aim**	**Research Design**
Beremenyi et al. (2016), Romania, Spain, United Kingdom, Lithuania, Italy, Cyprus, France, Bulgaria, Ireland	2012–2015	Schools, communities, nongovernmental organisations	500 children aged 12–18 years	Roma youth victims of discrimination and violence in community and schools, early forced marriage, educational neglect, and poverty	Design antidiscrimination policies to meet children's needs	*Mixed design* *Quantitative*: Survey carried out by children *Qualitative*: Interviews carried out by children *Action research*: Development and implementation of action plans
Change Factory (2020), Norway	2020	Local child protection offices	110 children aged 6–12 years	Involved with child protection system (receiving care or support)	Evaluate the service of child protection system	*Qualitative*: Semistructured focus groups including individual and group assignments. Most children participated in two meetings

Table 2.1. *(Continued)*

Author (Year), Country	Study Duration	Setting	Sample	Children's Key Vulnerability	Research Aim	Research Design
David-Kacso et al. (2021), Romania	2021	Schools in poor rural communities	2,029 children aged 9–18 years attending elementary, middle, or high school	Victims of school violence (by peers or teachers)	Improving school climate and reducing violence in schools	*Mixed design* *Quantitative*: Online survey of school climate *Qualitative*: Focus groups about the survey's items *Action research*: Development of action plans to improve school climate and reduce violence
Fuentes-Peláez et al. (2023), Spain	2021	Nonkinship foster care	17 children aged 6–11 years or 12–17 years	Live in foster care	Evaluate the service of foster care	*Qualitative*: Gamified interview: 'Play & Talk', including a version for each age group

Table 2.1. *(Continued)*

Author (Year), Country	**Study Duration**	**Setting**	**Sample**	**Children's Key Vulnerability**	**Research Aim**	**Research Design**
Korhonen, Lindholm, et al. (2023), Sweden	2021	National competence centre (Barnafrid)	14 children aged 15 or 18 years attending high school	Exposure to violence of different types, e.g., at school, domestic, online	Understanding the types of violence children are at risk of being exposed to	*Qualitative*: Workshop
Korhonen and Mattelin (2023), Sweden	2022	Schools and libraries	36 newly arrived children with refugee backgrounds aged 13–18 years attending high school	Exposure to community violence	Evaluate exposure to violence and other adversities among refugee children in the country of resettlement	*Qualitative*: Workshop including different activities, e.g., identify critical words related to violence in public places
Laszlo et al. (2023), Romania, Republic of Moldova, Ukraine	2020–present	High schools in Romania	12 children aged 15–18 years originally from Moldova	Left behind by parents who engaged or are engaging in labour migration	Understanding the life experience of stay-behind children and its impacts	*Qualitative*: Individual interviews, family interviews, focus groups

Table 2.1. *(Continued)*

Author (Year), Country	**Study Duration**	**Setting**	**Sample**	**Children's Key Vulnerability**	**Research Aim**	**Research Design**
Montserrat et al. (2022), Spain	2021	Carried out online, children participated from their homes or school	45 children, active members of local children's councils aged 10–16 years attending primary or secondary school	Exposure to gender-based violence in school	Explore children's perspectives on gender-based violence and the barriers and facilitators to disclosure in the school context	*Qualitative*: Focus groups
Nikolaidis, Petroulaki, et al. (2018), Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Macedonia, Greece, Romania, Serbia, Turkey	2013	School	42,194 children aged 11, 13, or 16 attending school	Exposure to violence	International comparison of the prevalence of exposure to violence	*Mixed design* *Quantitative*: ICAST-CH survey: Child violence exposure screening tool (a 38-item self-report measure for children developed by ISPCAN)

Table 2.1. *(Continued)*

Author (Year), Country	Study Duration	Setting	Sample	Children's Key Vulnerability	Research Aim	Research Design
						Qualitative: Focus groups including 392 children
Nikolaidis, Ntinapogias, et al. (2018), Greece	2018	Open hospitality centres (camps)	38 Farsi- and Arabic-speaking refugee children aged 8–17 years	Refugee	Evaluate the municipal child protection system services for refugee and migrant children	*Qualitative*: Structured focussed groups including group protocol and a series of mock cases (vignettes)
Fernandes and Pereira (2023), Portugal	2013–2015	Schools and neighbourhoods in deprived communities associated with crime and deviant and risk behaviours, e.g., domestic violence, negligence, and abuse	38 children aged 9–12 years old	Living in social deprivation and neglect	Evaluate children's needs and means to achieve them	*Qualitative*: Interviews, observations, analysis of text, field notes drawing, photographs, and videos

Table 2.1. *(Continued)*

Author (Year), Country	**Study Duration**	**Setting**	**Sample**	**Children's Key Vulnerability**	**Research Aim**	**Research Design**
Rácz (2017), Hungary	2013–2014	Foster care, residential care	35 children aged 15–20 years	Living in institutional care (victims of neglect)	Evaluate the service of child protection system	*Qualitative*: Parliament discussion on one general open question (children write their answers)
Rácz (2019), Hungary	2017–2020	Foster care, residential care	21 children aged 14–18 years or 19–25 years	Living in institutional care (victims of neglect)	Evaluate the service of child protection professionals and understand the meaning of family	*Qualitative*: Semistructured focus groups for each age group
Rácz and Sik (2023), Hungary	2020–2021	Local child protection services	50 children aged 14–25 years	Involved with protection system e.g., mental health problems, psychosocial disabilities, no contact with family of origin, neglect and abuse, living in foster care	Develop apps to support young people in everyday life situations when moving out of care	*Qualitative*: Focus groups and interviews about the design of the app as well as later feedback on using the app

Table 2.1. *(Continued)*

Author (Year), Country	**Study Duration**	**Setting**	**Sample**	**Children's Key Vulnerability**	**Research Aim**	**Research Design**
Rockinghorse Childrights (2021), Hungary	2021	Online	101 children aged 14–20 years attending elementary and secondary schools	Exposure to internet violence	Evaluate children's knowledge and opinions on internet violence (i.e., cyberbullying)	*Quantitative*: Online survey
Sani et al. (2021), Portugal	2018	Clinics or sport facilities	40 children aged 12–18 years attending school: 20 undergoing psychological counselling (clinical group) and 20 without clinical follow-up (nonclinical group)	Multiple exposures to violence	Comparison between clinical and nonclinical children in relation to multiple victimisation and polyvictimisation	*Quantitative*: Survey on exposure to 36 types of victimisation
Voicu et al. (2016), Romania	2010–2012	Schools	30 children aged 11, 14, or 16 years	Victims of family violence	Understanding children's opinion on research ethics (i.e., necessity of parental consent)	*Mixed design*: *Quantitative*: Survey *Qualitative*: Structured focus groups

When Children Participate

Children's age ranged from 3 to 18 years, with some studies also including young adults up to 25 years old. Only four studies involved children younger than eight, including one study with children as young as three.

Turning to the stage in the research process in which children were engaged, relevant findings are summarised in Table 2.2. As shown in the table, children were not included in all stages of the research process.

In many studies ($n = 10$), children were only engaged in one task, and in a few studies ($n = 6$), children were involved in either two or three tasks. In three studies, children engaged in either four, five or six research tasks.

Children's involvement was most missing in the initial stage of framing the study, including making decisions about the research questions, design and methods and preparing the study's instruments. Only four studies indicated children's participation in the task of preparing tools: In two studies, children were consulted about the study survey via focus groups (David-Kacso et al., 2021; Nikolaidis, Petroulaki, et al., 2018); in one study, children tested the tool in a pilot study (Fuentes-Peláez et al., 2023); and in one study, children and adults worked together on designing the research interview guide and invitation letter for possible participants (Laszlo et al., 2023).

Children were mostly involved in the stage of conducting the study, particularly the data collection task. All studies ($n = 19$) included children in collecting data. Four studies also involved children in analysing the data and drawing conclusions.

Participation in the final stage of the research process that focuses on dissemination of study results was infrequent and reported in only six studies. In these studies, children were involved in tasks such as producing the final research report, drafting recommendations and action plans, or presenting outcomes to professionals and policy-makers at conferences or official meetings (Beremenyi et al., 2016; David-Kacso et al., 2021; Korhonen, Lindholm, et al., 2023; Laszlo et al., 2023; Fernandes & Pereira, 2023; Rácz & Sik, 2023).

How Children Participate

Many studies ($n = 13$) applied a qualitative research design, using mainly interviews and focus groups as data collection methods. A few studies incorporated child-friendly interviewing techniques such as using drawings and pictures (Árnadóttir & Isdóttir, 2019; Fernandes & Pereira, 2023), the 'play and talk' game (Fuentes-Peláez et al., 2023; for more information, see Chapter 6) or asking children to hang notes on a 'wish tree' (Árnadóttir & Einarsdóttir, 2023; for more information, see Chapter 9). Four studies used mixed-methods designs that integrated data collected by surveys and focus groups. Two studies applied a quantitative approach, using surveys to collect data.

How Much Children Participate

Using Shier's (2019) matrix, we classified children's participation in distinctive research tasks according to the level of decision-making power and control they

Table 2.2. Summary of Studies (n = 19) by Tasks in Which Children Participated and Level of Participation (No Participation, Consulted, Collaborated, Led).

Research Stage	**Framing the Study**			**Conducting the Study**			**Disseminating the Study Results**		
Author (Year)	**Research Question**	**Research Design and Methods**	**Research Tools**	**Participant Recruitment**	**Data Collection**	**Data Analysis**	**Production of Report or Recommendations**	**Dissemination of Report or Findings**	**Advocacy for Policy Impact**
Árnadóttir and Isdóttir (2019)					▨				
Change Factory (2020)					▨				
Rockinghorse Childrights (2021)					▨				
Korhonen and Mattelin (2023)					▨				
Rácz (2017)					▨				

Table 2.2. *(Continued)*

Research Stage	Framing the Study			Conducting the Study			Disseminating the Study Results		
Author (Year)	**Research Question**	**Research Design and Methods**	**Research Tools**	**Participant Recruitment**	**Data Collection**	**Data Analysis**	**Production of Report or Recommendations**	**Dissemination of Report or Findings**	**Advocacy for Policy Impact**
Montserrat et al. (2022)					▨				
Rácz (2019)					▨				
Sani et al. (2021)					▨				
Voicu et al. (2016)					▨				
Nikolaidis, Ntinapogias, et al. (2018)					▨				
Fuentes-Peláez et al. (2023)			▨		▨				
Nikolaidis, Petroulaki, et al. (2018)			▨		▨				
Rácz and Sik (2023)					▨		▨		

Table 2.2. *(Continued)*

Research Stage	**Framing the Study**			**Conducting the Study**			**Disseminating the Study Results**		
Author (Year)	**Research Question**	**Research Design and Methods**	**Research Tools**	**Participant Recruitment**	**Data Collection**	**Data Analysis**	**Production of Report or Recommendations**	**Dissemination of Report or Findings**	**Advocacy for Policy Impact**
Árnadóttir and Einarsdóttir (2023)					░	▓			
Korhonen, Lindholm, et al. (2023)					▓		▓	▓	
Beremenyi et al. (2016)					■			▓	■
Fernandes and Pereira (2023)					▓	▓		■	■
David-Kacso et al. (2021)			░		░	▓		▓	■
Laszlo et al. (2023)			▓	■	▓	▓	▓	▓	

Note: White represents tasks in which children were not involved; light grey represents tasks in which children were consulted by adults; dark grey represents tasks in which children collaborated with adults; and black represents tasks that children led.

exercised, as illustrated in Table 2.2. Overall, as shown in the table, for most research tasks (*n* = 19 of 39 tasks), children had a low level of decision-making power and control, mainly being consulted by adult researchers. For example, most studies (*n* = 15) involved adults surveying or interviewing children (as individuals or in groups) on their opinions.

Next were tasks (*n* = 14) on which children collaborated with adult researchers. Adults and children worked together mainly on data collection activities – for example, through a joint workshop (Korhonen, Lindholm, et al., 2023) or by conducting interviews and observations (documented in notes, pictures and videos) in schools and neighbourhoods (Laszlo et al., 2023; Fernandes & Pereira, 2023). They also collaborated on data analysis procedures, such as identifying key problems in school and neighbourhood environments (David-Kacso et al., 2021; Fernandes & Pereira, 2023), and presenting the research findings at conferences and meetings with formal policymakers such as local authorities, either themselves (Beremenyi et al., 2016; David-Kacso et al., 2021) or by generating materials later presented by the researchers (Laszlo et al., 2023). In one example, a video was presented at a national meeting on violence against children (Korhonen, Lindholm, et al., 2023).

Less common were tasks (*n* = 6) that children led, directed and decided independently, which were evident in four studies. For example, in a study about transnational families affected by labour migration, children identified and recruited research participants (Laszlo et al., 2023). They later had the opportunity to choose whether to attend interviews led by an adult researcher or conduct the interviews themselves (individually or in pairs) with adult supervision. In an international study focused on the Roma population, children organised and carried out independent data collection activities using surveys and interviews (Beremenyi et al., 2016).

Of note, children in some studies engaged independently in activities to disseminate study outcomes. Children used various means to raise awareness, advertise their ideas for solutions and promote policy change, including newspapers, documentaries, puppet shows and approaching influential policy-makers such as a city mayor (Beremenyi et al., 2016; Fernandes & Pereira, 2023). The international study among Roma population also described a few cases in which young people's endeavours had on-the-ground consequences, such as building a bicycle path to the Roma community or establishing better public lighting (Beremenyi et al., 2016).

Discussion

The objective of the current chapter was to provide a comprehensive reflection on recent participatory research projects with children on violence and maltreatment carried out by WG3 members and their colleagues to review current achievements and inform future progress. In particular, we wanted to know why, when, how and how much children participate in research.

In general, our analysis shows that children can participate in research about highly sensitive life experiences involving, for example, interpersonal violence victimisation, family breakdown and growing up in severely deprived environments, such as refugee camps and poor neighbourhoods. Nonetheless, a more nuanced inspection revealed that children's participation has been actualised in very different ways in research.

In this overview, we considerably expanded Shier's (2019) matrix for analysing children's engagement in research processes. Originally, the tool was designed to help scholars plan participatory research by purposely directing them to consider the level of power and control assigned to children regarding decisions during the nine stages of the research process. In this chapter, we utilised the tool to analyse the studies' actual rather than intended participatory arrangements. Furthermore, the utilisation of the adapted matrix in our analysis went beyond assessment of an individual study and enabled comparison of studies and identification of common patterns. This approached increased our knowledge of the application of the participatory approach in a transparent way.

Generally, we identified two key types of participatory research, following the conceptualisation of participation as a continuum ranging from a traditional adult researcher-led approach to children as researchers or co-researchers (Kiili & Moilanen, 2019; Lansdown & O'Kane, 2015; Shier, 2019).

In effect, most studies only slightly diverted from the traditional arrangement of an adult researcher-led study. In 10 studies, children only engaged as providers of data – i.e., as consultants to adults in data collection (Árnadóttir & Isdóttir, 2019; Change Factory, 2020; Korhonen & Mattelin, 2023; Montserrat et al., 2022; Nikolaidis, Ntinapogias, et al., 2018; Rácz, 2017, 2019; Rockinghorse Childrights, 2021; Sani et al., 2021; Voicu et al., 2016). In four other studies, children were involved in a second task, yet other than one exception, still as consultants (Árnadóttir & Einarsdóttir, 2023; Fuentes-Peláez et al., 2023; Nikolaidis, Petroulaki, et al., 2018; Rácz & Sik, 2023).

Fewer studies ($n = 5$) actualised participation in a way that inclined towards the other end of the continuum marked by children-led research (Beremenyi et al., 2016; David-Kacso et al., 2021; Korhonen, Lindholm, et al., 2023; Laszlo et al., 2023; Fernandes & Pereira, 2023). In these studies, children's participation was highly meaningful in terms of both quantity and quality. Children were engaged in more tasks (between three to six research tasks) and had more decision-making power and control – i.e., as collaborators and leaders. In addition, children's participation in these studies was also very effective because children utilised the research findings to raise awareness, make an impact in the research community and influence policy change. Considering the argument by which participation should be defined by its results (Skauge et al., 2021), these studies demonstrated successful participation.

We hope that these examples of participation that enable children to incorporate their perspectives throughout the research process will inspire scholars to involve children in studies in a more significant and equal way.

Our analysis also uncovered specific areas where more progress is required. Accordingly, we suggest the following:

(1) It is important to openly discuss the aim of children's inclusion in research. Our overview shows that children don't have an impact on the topic of empirical inquiry. None of the studies engaged children at the initial stage of deciding on the research question. Arguably, that for participatory research to guarantee children's best interests, studies should address questions or problems that are important to children from their perspective. Research whose starting point is problems framed by children can serve important launch pads for later developments of more pertinent and appropriate solutions or interventions. Moreover, allowing children a leading role in deciding on research objective is particularly important in this field, because there are no clear, unified and agreed-upon definitions of child maltreatment and violence against children (Gilbert et al., 2009; Nouman & Alfandari, 2020).

(2) Greater attention should be given to increasing opportunities for young children to participate in research. Studies in our overview followed the general tendency found in participatory research (Lundy et al., 2011) of being skewed towards older children and young people and, thus, insufficiently represented young children's perspectives and life experiences. These younger age groups have relationships with adults that are marked by the greatest asymmetrical power differences (Lundy et al., 2011) and are excluded from the exploration and understanding of experiences of violence and maltreatment. The lesson learned from the limited available literature on the topic is that under facilitating conditions – for example, provision of guidance and support – younger children can meaningfully participate (e.g. as co-researchers) in some aspects of the research process and effectively contribute to research outcomes (Lundy et al., 2011).

(3) Research can benefit from utilising more child-appropriate data collection methods that are less foreign to children than self-report questionnaires and formal interviews (Carnevale, 2020). The overview provided examples of creative participatory data collection strategies, particularly used for research with very young children (e.g. games, wish tree, drawing), which can inspire future research (Árnadóttir & Einarsdóttir, 2023; Árnadottir & Isdóttir, 2019; Fuentes-Peláez et al., 2023). Allowing children influence over decisions relating to the research methodology can provide significant understanding of how to enable them to express their opinions and share their experiences.

(4) In the wake of scholars' outcry over insufficient guidance on how to engage children meaningfully, authentically and effectively in the research process (Liebenberg et al., 2020; Pavarini et al., 2019; Schelbe et al., 2015), we call on researchers to share their experiences, achievements, disappointments and missteps when including children in empirical studies. Scholars from non-English-speaking countries are particularly encouraged to publish their work in international journals and conferences. As shown by this overview, their work can support the accumulation of valuable evidence-based knowledge and skills regarding participatory research with children about sensitive topics.

(5) Finally, we suggest that future research should also strive to capture children's reflective accounts about their participation experience, a topic that was very much missing in the studies reviewed and has gained little attention in the literature (Pavarini et al., 2019). In one study included in the overview, children appreciated being listened to and able to express their opinions (Korhonen & Mattelin, 2023). Encouraging children's ongoing reflection throughout the research process is particularly important when exploring their difficult and violent life experiences. Children's feedback and reflections should be given serious weight in the development of future participatory research.

Conclusions

Meaningful and effective participation of children in research about violence and maltreatment is highly challenging and yet a feasible practice. Building on the existing evidence base, we suggest that further efforts are needed to advance participatory research with children. Providing children with decision-making power and control over the subject or focus of the scientific exploration and giving considerable weight to children's reflective accounts about their participatory experience are important steps forward.

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Chapter 3

The Right of Children to Be Heard in Participatory Research on Violence

Athanasios Ntinapogias and George Nikolaidis

Abstract

Involvement of children in research on different aspects of children's rights, including research on violence against children, is continuously increasing, as is the interest in participatory approaches (European Agency for Fundamental Rights [FRA], 2014; Larsson et al., 2018; UN Committee on the Rights of the Child, 2011). Svevo-Cianci et al. (2011) noted that 'as researchers commit to learning from community members, including children and adolescents themselves, it has become more clear that an understanding of the lived reality and definition of violence for children in their individual communities, is essential to envision and implement effective child protection' (p. 985).

In this chapter, the legislative context regarding children's rights to be heard and participate is initially discussed; currently applied age requirements for children to acquire rights across the countries of the European Union (EU) are briefly presented; and children's potential roles and relevant provisions for their participation in social research are explored. The last part is dedicated to the presentation and discussion of the General Data Protection Regulation (GDPR; Regulation [EU] 2016/679, 2016) – specifically, children's personal data–related recitals and articles; the importance of the definition of a legal basis for personal data processing according to the GDPR, including consent; and the necessary information to be provided to children before their data are processed.

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Keywords: Right to be heard; child participation; cross-national data; participation ethics; consent; data protection

Introduction

According to the General Comment 12 released by the UN Committee on the Rights of the Child (2009), children's participation involves ongoing processes, which include 'information-sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes' (p. 3). In 2018, the Secretariat of the Lanzarote Committee drafted guidelines for the implementation of child participation in relation to 'the protection of children against sexual exploitation and sexual abuse facilitated by information and communication technologies' (Title). Child participation, in this document, means that all children, individuals or groups, without discrimination on any grounds, have the right, means, space, opportunity and where necessary, support to freely express their views, be heard and contribute to decision-making on matters affecting them (Secretariat of the Lanzarote Committee, 2018). It specifically mentions that children's views should be given due weight in accordance with their age and maturity; the rights of children and young people to participate applies without discrimination on any grounds, including race, ethnicity, colour, sex, language, religion, political or other opinion, national or social origin, property, disability, birth, sexual orientation or other status; and particular efforts should be made to enable participation of children and young people with fewer opportunities, including those who are vulnerable or have special needs.

However, despite general agreement about children's participation, particularly in social research and development of interventions, when research focusses on sensitive issues, potential children participants are treated as vulnerable beneficiaries who should be protected by adults rather than as rights holders entitled to contribute to the decision involved. This leads to strict gatekeeping procedures that prevent some children from participating, compromising their participation rights (Powell & Smith, 2009). As a result, when researchers try to obtain approval and support for children's participation, they have to deal with challenges often related to different perspectives or conflicting interests, needs, or expectations from relevant adult stakeholders, including parents and professionals working with children and human research ethics committees (Powell et al., 2020). In this context, research focussing on violence against children raises concerns related to issues involving the research process as a whole and specific aspects such as obtaining consent, confidentiality and protection of personal data (Laws & Mann, 2004).

Strengthening Child Participation

On 24 March 2021, the European Commission adopted the European Union (EU) strategy on the rights of the child, which includes more than 40 actions that the commission will implement or start implementing by 2024. To improve the situation, child participation in political and democratic life was included as the first thematic area of the strategy, understood as the right for children to be heard and an obligation for adults to facilitate and organise their involvement in a meaningful, inclusive and safe way. Safe child participation, which is a precondition of participation, means that children have a safe space to express their views, participate in activities, complain and voice their concerns. Inclusive child participation means that efforts are made to include and engage with children from different geographical areas, socio-economic backgrounds and minority groups, including children with disabilities. Such participation ensures gender and age diversity. Meaningful child participation is based on mutual respect, transparent and voluntary, moderated using child-friendly tools and working methods, and supported by training and access to information. Any activity involving children must include access to clear and age-appropriate information about the objectives, procedures, timing, involvement of third parties and safety procedures, and must finish with a feedback or follow-up session. In the same line, the third thematic area of the EU strategy on the rights of the child concerns EU actions that help children become free from violence; specifically, the first of 10 principles for integrated child protection systems states that every child must be treated as a unique and valuable person with due regard to their right to participation.

Age Requirements for Children to Acquire Rights Across the EU

In 2017, European Agency for Fundamental Rights (FRA) published a mapping of age requirements for children to acquire rights across the EU based on data collected through FRANET, FRA's multidisciplinary research network, through 2016. The objective was to assist member states in addressing children's rights relevant issues and facilitate the EU in exercising its competence to support and coordinate member states' actions related to children and youth. Specific data values for all countries and variables are available online for several policy areas, including, among others, children's right to access justice, relevant procedural rights such as to be heard and right to provide consent in the digital world. Although no updated mapping for age limits for children to participate in research is included, selected age requirements for children to acquire their rights are presented here.

Concerning the right to be heard (FRA, 2018), the age at which a child can formally issue a complaint of abuse or violence to judicial and law enforcement authorities varies among EU countries: In 18 countries, there is no minimum age (Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Germany, Denmark, Estonia, France, Italy, Luxembourg, Latvia, Malta, Poland, Sweden, Slovenia, Slovakia and the United Kingdom). Age thresholds in the remaining member states are as follows: 12 years old (Greece); 14–16 years old (Croatia, Finland, Hungary, Lithuania, Netherlands and Portugal) and 18 years old (Ireland, Romania and Spain). As for the age at which a child has the right to be heard as a victim of violence, abuse or neglect, 13 countries have no minimum age (Austria, Belgium, Estonia, Greece, France, Lithuania, Luxembourg, Latvia, Poland, Portugal, Romania, Slovakia and the United Kingdom), whereas age thresholds in the remaining countries are 10–12 years old (Bulgaria, Czech Republic, Italy, Netherlands and Spain) or 14–16 years old (Croatia, Denmark, Finland, Hungary and Sweden). Last, five countries have no relevant regulation (Cyprus, Germany, Ireland, Malta and Slovenia).

Information regarding requirements for children in the digital world (FRA, 2017) focusses on the age at which children can provide consent to disclose their images and personal data and consent to the use of their personal data. Requirements in the first case are 15 or 16 years old (Finland, Hungary, Netherlands, Romania and Spain) or 18 years old (Croatia, Bulgaria, Estonia, France, Greece, Italy, Latvia, Lithuania and Poland). In four countries, age limits depend on the child's maturity (Belgium, Czech Republic, Germany and Slovakia), whereas in 10 countries, no relevant data are available (Austria, Cyprus, Denmark, Ireland, Luxembourg, Malta, Portugal, Slovenia, Sweden and the United Kingdom). As for the latter topic, the age at which children can provide consent for the use of their personal data is 14–16 years old (Bulgaria, Hungary, Netherlands and Spain) or 18 years old (Croatia, Cyprus, Estonia, Finland, France, Greece, Ireland, Italy, Latvia, Portugal, Romania and Slovenia). In seven countries, the age limit depends on the child's maturity (Belgium, Czech Republic, Denmark, Germany, Malta, Slovakia and Sweden), whereas in five countries, no relevant data were available as of April 2016 (Austria, Lithuania, Luxembourg, Poland and the United Kingdom).

Role of the Child Participating in Social Research

According to Shier's (2001) pathways to participation model, children's and young people's participation in research can be distinguished at five levels, from participating as a passive informant to contributing as an active agent in a partnership position. Similarly, a scoping review by Larsson et al. (2018), which analysed 41 studies published during 2000–2017, found that the level of children's and young people's participation in research varied. In some cases, they were involved only as informants; in other cases, they had greater participation in quantitative and qualitative terms; and in yet other cases, they were active agents involved as coresearchers, although the distribution of participation was not equal on these different levels. Therefore, the role of children in research ranges from being informants, or a source of knowledge, by simply participating as a subject of the research (although they are informed, are listened to, express their views and are taken into account, thus influencing the outcome) to being a producer of knowledge, having a role similar to a coresearcher, who may initiate projects and share decision-making powers. In practice, as suggested in the literature, various degrees between those two levels of participation can be identified.

Considering the issues of when and how children participate in research, Broström (2012) suggested that participation is considered more meaningful if the children are involved at all stages of the research, including the research design, data collection, interpretation and analysis, and dissemination of the findings. Such meaningful involvement of children can have benefits for both the research and the child because child participation increases the validity of data (insider perspective) and children gain knowledge and valuable skills for cultural and political participation. On the other hand, participation of children in research involves several challenges. Among the main challenges are the relationship between vulnerability and participation, especially for specific groups of children such as those in alternative care (Garcia-Quiroga & Salvo Agoglia, 2020); the power relationship between adult and child; the adult perspective on children (insider and outsider perspectives are difficult to balance); and child protection issues such as appropriately ensuring informed consent, handling disclosure and emotional well-being, and protecting children's personal data (Broström, 2012).

Provisions for Children's Participation in Social Research

To ensure that the best interests of the children is the primary consideration, research in general has to be carefully designed, based on appropriate consultation, and properly conducted, whereas applied methodology needs to be in alignment with relevant rules, regulations and guidelines; suitable to the research purpose and inclusive concerning all voices that need to be heard.

A non-homogeneous situation similar to that of age requirements for children to participate by acquiring their rights across EU countries was mapped regarding children's participation in research. In 2014, FRA published the results of this mapping project concerning legal requirements and ethical codes of conduct of child participation in research in EU member states. According to this effort, such provisions are in place in all EU countries, although each country has different rules and prerequisites for the participation of children in research, either more general rules or age-specific guidelines. These include legal frameworks and ethical codes of conduct, particularly concerning the role of children and parents, role of schools, residential care institutions or other settings, procedures for granting ethical approval and processes to ensure informed consent.

Provisions related to child participation in research can be identified in country-specific documents, including personal data protection or other relevant regulations and laws; articles in civil codes; statutory instruments; child protection–related acts; codes of ethics or conduct of professional associations; codes of ethics for research or social research; national standards; and recommendations and operational guidelines issued by ethical review committees or national data protection authorities.

Age is often a crucial parameter for child participation in research because it is related to the child's capability to provide consent, which is a prerequisite for participation in social or similar research. Therefore, it is important for researchers to be aware of the age when a child can freely provide their consent to participate in a research programme. What are the accepted types of consent that a child can provide to participate in research? What are the conditions (other than age) under which the child does not have the capacity to provide consent? Are there any specific provisions and guidelines for the assessment of a child's level of maturity and capacity for insight? Researchers should also be aware of the role of the parents or guardians of the child, if and when parental consent is required, and the accepted types of consent (active and passive) that a parent can provide for the child to participate in research. Especially regarding parental consent, the situation varies considerably – in some countries, parental consent is always required for children up to 18 years old; whereas other countries require parental consent for children younger than 15 or 16 or younger than 14 years old; and in some countries, parental consent varies depending on contexts and is required for children up to 18 years old in school settings (FRA, 2014).

In case of research in specific settings (such as schools and residential care institutions) or specific ways (for example, online), researchers also should be aware of whether there are setting-specific consent-related provisions for surveys, who can provide consent for child participation apart from parents (such as guardians or teachers), whether there are specific predefined consent forms in each case and what are the mandatory procedures. Some of these elements can be conditional and depend on factors like: (1) setting type (e.g. for schools: public or private and grade; for residential care institutions: type, legal status as public, private or charitable, and age group of children); (2) geographical region (potential differences from municipality to municipality); (3) children's conditions (disability or other conditions); (4) research topic (especially for sensitive issues like drugs use and child maltreatment); and (5) data to be collected (whether personal data are included, anonymous data etc.).

As for internet-based research (online surveys), researchers should be aware whether there are additional provisions, apart from consent-related provisions for research with children in person, and provisions on the type of children's data that can be collected, processed and disseminated.

Last, researchers should be aware of the procedures and prerequisites to apply for ethical approval of their research protocols involving children. They should be aware of whether there are specific institutions involved in this process (national or local ethics-related committees or services under relevant ministries such as the Ministry of Education) and specific procedures, such as whether they should provide a written request to competent authorities in advance that includes details on research protocols (methods, procedures, tools, informed consent forms, data collection, processing and dissemination) and receive written feedback before they start the research (opinion or final decision regarding approval or rejection).

General Data Protection Regulation

The General Data Protection Regulation (GDPR) came into force on 25 May 2018, repealing the 95/46/EC Data Protection Directive. As stipulated in the GDPR, although a high level of protection must be ensured with regard to personal data processing, this should be balanced against other fundamental rights in accordance with the principle of proportionality.

According to the GDPR (Article 4 Definitions, p. 33), ‘personal data’ means ‘any information relating to an identified or identifiable natural person (“data subject”); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person’, whereas ‘processing’ means ‘any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction’.

To this end, any activity involving personal data processing, including research activities in which children participate in any possible way, is subject to the GDPR. There is only one condition, as described in Recital 26, where the regulation is not applicable: when data are anonymous and processing concerns anonymous information, including for statistical or research purposes. Specifically, the principles of data protection are not applicable to information that does not relate to an identified or identifiable person or personal data rendered anonymous in such a manner that the data subject is not identifiable.

Therefore, any research activity involving child participation of any extent, ranging from children as passive informants to co-authors, and not fully anonymous personal data should take into account the provisions of the GDPR for the protection of personal data. It should be clear to researchers that personal data protection provisions and required protection measures are different than prerequisites for acquiring ethical approval for research with child participants.

Children’s Personal Data–Related GDPR Recitals and Articles

Although all GDPR provisions apply also to children, the following section outlines GDPR recitals and articles related to the protection of children’s personal data – namely, the main points of Recitals 38, 58, 65 and 75 and Articles 5, 6, 8, 12 and 40.

Recital 38 notes that children merit specific protection regarding their personal data because they may be less aware of the risks, consequences and safeguards concerned and their rights in relation to the processing of personal data. It clarifies, however, that the consent of the holder of parental responsibility should not be necessary in the context of preventive or counselling services offered directly to a child.

Recital 58 provisions are related to the principle of transparency of information; concerning children, it notes that given that children merit specific protection, any information and communication where processing is addressed to a child should be clear and plain language that the child can easily understand.

In Recital 65, the right of participants to have their personal data rectified, if and where needed, and the ‘right to be forgotten’ are included. These rights also apply for cases where consent was given in the past, when a person was child and personal data continue to exist and are processed when the person is an adult. A classic example here is Amber Alert announcements for missing children. Automated processing of personal data evaluating the personal aspects relating to a person (profiling) is not allowed for children.

Finally, Recital 75 notes that personal data processing potentially implies a risk to the rights and freedoms of participants, which could lead to physical or other type of damage, particularly when the personal data of vulnerable people – especially children – are processed. People should be explicitly informed about potential risks of personal data processing in advance (before processing takes place).

In Article 5, the main principles for processing of personal data are presented. The controller of the data shall be responsible for and able to demonstrate compliance with according to these principles:

- Lawfulness, fairness and transparency: Personal data should be processed lawfully, fairly and in a transparent manner in relation to the data subject.
- Purpose limitation: Personal data should be collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes should not be considered incompatible with the initial purposes.
- Data minimisation: Personal data should be adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.
- Accuracy: Personal data should be accurate and where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate with regard to the purposes for which they are processed are erased or rectified without delay.
- Storage limitation: Personal data should be kept in a form that permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods if they will be processed solely for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes subject to implementation of the appropriate technical and organisational measures required by the regulation to safeguard the rights and freedoms of the data subject.
- Integrity and confidentiality: Personal data should be processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and accidental loss, destruction or damage, using appropriate technical or organisational measures.

Article 6, relating to the lawfulness of processing, mentions that in some cases, the legal basis for personal data processing could be the legitimate interests of the controller or a third party. However, this is not possible if such interests are overridden by the interests or fundamental rights and freedoms of the data subject, which require protection of personal data, particularly if the data subject is a child.

Article 8 contains provisions about the conditions applicable to a child's consent in relation to social information services (e.g. social networks or other online services). In such cases, the processing of the personal data of a child is lawful if the child is at least 16 years old. If the child is younger than 16, such processing is lawful only if and to the extent that consent is given or authorised by the holder of parental responsibility over the child. Member states may provide for a lower age for those purposes by law, provided that this lower age is not below 13 years.

In terms of transparency (Article 12 regarding transparent information, communication and modalities for the exercise of the rights of the data subject), there are clear provisions requiring the controller to take appropriate measures to provide information to data subjects that are related to processing of personal data. The controller should provide such information in a concise, transparent, intelligible and easily accessible form using clear and plain language, particularly for any information addressed to a child. The information should be provided in writing or by other means, including electronic means, where appropriate. When requested by the data subject, information may be provided orally, provided that the identity of the data subject is proven by other means.

Last, Article 40 suggests associations and other bodies representing categories of controllers or processors to prepare codes of conduct or amend or extend such codes to specify the application of the regulation, such as regarding the information provided to and the protection of children and the manner in which the consent of the holders of parental responsibility over children is to be obtained.

Legal Basis for Personal Data Processing According to the GDPR and Child Participation

As previously described (GDPR, Article 6, p. 36), to comply with data protection law, before researchers can collect and use any personal data, they need to establish a 'legal base'. Namely, at least one of the following must occur:

- the data subject has consented to the processing of his or her personal data for one or more specific purposes;
- processing is necessary for the performance of a contract to which the data subject is party or to take steps at the request of the data subject prior to entering into a contract;
- processing is necessary for compliance with a legal obligation to which the controller is subject;
- processing is necessary to protect the vital interests of the data subject or another person;
- processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller and

- processing is necessary for the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject, which require protection of personal data, particularly if the data subject is a child.

Processing of ‘special category’ data such as religion, race and ethnic origin needs a further legal basis that could involve public interest. Recital 52 notes, among other provisions, that derogating from the prohibition on processing special categories of personal data should also be allowed under certain conditions. Such a derogation may be made for health purposes, including public health and the management of health care services, especially to ensure the quality and cost-effectiveness of procedures used for settling claims for benefits and services in the health insurance system or for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes.

Consent as a Legal Basis for Processing Personal Data

The GDPR imposes very strict requirements for consent to be valid (including use of information and communications technologies): it must be freely given (Recital 43); specific; informed (covering all relevant purposes for the processing by all relevant parties, appropriate and age-adapted) and unambiguous. Also, positive action is required to opt in. Failure to opt out does not constitute consent for the purposes of the GDPR. Moreover, individuals may withdraw their consent at any time.

If consent is selected as a legal base for processing personal data in research, it should always be considered whether the individual child has the competence to understand and consent. If not, the child’s consent is not valid. If a child is not competent to give consent, the consent of someone with parental authority over them will need to be obtained (and such consent should be verified, where appropriate). Agreement of a teacher in the child’s school, for example, is not sufficient to constitute consent for the purposes of the GDPR. Researchers should think carefully about relying on consent as their legal basis for processing personal data or if it would be more appropriate to work on another legal basis, such as a task carried out in the public interest.

Obtaining informed consent from individual participants when consent is not the legal basis for processing is usually necessary to obtain ethical approval for research involving children. Consent to participate in research, however, is not the same as using consent as the legal basis for processing personal data under the GDPR. For example, people may be asked to consent to participate in research and informed that if they agree to participate, data about them will be processed for a task in the public interest. In this case, the legal basis for data processing is a task carried out in the public interest rather than consent (UCL Legal Services Data Protection Office, 2018). Consent to participate in a project obtained for ethical purposes must be also fully informed and freely given when a child is competent enough to consent to participate in a particular research intervention.

It is still a good practice to involve their family as part of the decision-making process unless the child asks the researcher not to do so. Therefore, it should be clear to researchers that there is a distinction between children's participation in research and processing of participating children's personal data. They need to obtain the informed consent of individual participants for their involvement in the research to obtain ethical approval of the research protocol. However, to use consent as a legal basis for processing of participants' personal data, they should clearly and appropriately inform the participants and ask they consent for processing their personal data.

Information to Be Provided to Children Before Their Data Are Processed

For the processing of personal data to be fair and lawful under the GDPR, individuals (here, children participating in research and their parents or guardians, where necessary) must receive information on the processing to be carried out, including for what reason the data will be used, with whom they will be shared and how long they will be kept for (fairness and lawfulness). Moreover, they have to be informed of the risks inherent in the processing and the safeguards in place in the context of the research (transparency). Information notices to children should be written in a concise, clear and plain style; age appropriate and presented in a way that appeals to a young audience. In case that the target audience covers a wide age range, provision of different versions of informational sheets and notices should be considered. In case that the research relies on parental consent as the lawful basis for processing, researchers should provide parents or guardians and children with separate and appropriately prepared privacy notices. To comply with the accountability requirement under the GDPR, controllers (here, the responsible researchers) must demonstrate compliance with data protection legislation, which practically means that, in addition to establishing a legal basis for processing, they documented the selected basis and kept evidence justifying the fair processing of data.

Preparing Child Participation in Social Research

Relevant information for provisions concerning child participation in social research, including research on violence, for each EU country was published by FRA, reflecting the situation as of 2014, as already discussed. To update this information, a tool for collecting European country-specific terms and provisions for children's participation in social research was developed in the context of a working group on 'promoting participatory approaches to child maltreatment surveillance' of the Euro-CAN Action's (2020) 'Multi-Sectoral Responses to Child Abuse and Neglect in Europe: Incidence and Trends'. The aim of this initiative is to update available information and add further information on developments at national and European levels since 2014, including the introduction of the GDPR in 2018, which is considered a milestone for personal data protection. Specifically, during the planning of research, researchers should be fully aware of what is required according to national legal frameworks and ethical codes of conduct for research involving children. They should know at what age a child has the legal capacity to make legally effective decisions – namely, the child is presumed by law to be competent – and whether there are consent-related obligations for child participation in social or similar research. Regarding children's role, researchers should know the age at which a child can freely provide consent to participate in research, the accepted types of consent that a child can provide (such as informed consent or assent, written or orally), and whether there are conditions (other than age) under which the child does not have the capacity to provide consent (for example, provisions for the assessment of the child's level of maturity and capacity for insight). As for the role of parents and caregivers, it should be clear when parental consent is required, the accepted types of consent that a parent can provide (active or passive, opt in or opt out), and any relevant procedural issues (such as timing of parental consent acquirement). If researchers are interested in conducting research in specific settings, such as schools or educational settings, residential care institutions and internet-based (online) surveys, they should know whether there are special consent-related provisions (such as forms or templates of consent forms that should be used) and whether the process depends on setting-specific factors – e.g. school type (public or private); grade (preschool, elementary, secondary); geographical region; participants' conditions (disabilities or other conditions); research topic (sensitive issues like drug use or maltreatment) and data to be collected (personal or anonymous data). Last, concerning ethical approval, researchers should know whether there are specific institutions or committees involved in ethical approval of social research protocols (methods, procedures, tools, data protection etc.) involving children and if so, if there are defined procedures that should be followed.

The updated version of such a mapping of what it is provisioned and required at a national level for the active involvement of children in research is expected to serve as a practical tool, especially for young researchers who are interested in conducting participatory research on topics like child protection and violence prevention–related issues.

Conclusion

Promoting the involvement and participation of children in social research, especially on the topic of child maltreatment, is considered an important step to strengthen children's rights to participate and be heard. Developments in legislation, however, such as the introduction of the GDPR, along with the existence of diverging rules and regulations in different EU countries, may represent a challenge for researchers when it comes to research projects on sensitive child well-being–related phenomena, especially when the research involves several countries. Rules and prerequisites should be fully considered and applied to ensure that relevant efforts are of benefit to children.

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Chapter 4

The Ethics of Research With Children on Violence Re-Examined

Maria Roth

Abstract

From an ethical point of view, the inclusion of children and young people in research is problematic due to their inability to give informed consent and meaningfully express their views. The ethical aspects of research are multiplied if the research participant might have experienced child abuse, neglect, exploitation, or other forms of violence or assisted in such acts. Talking about victimization might be difficult and generate a sense of betrayal of attachment figures. On the other hand, the usual ethical procedure of asking parents or other caretakers to give consent for their children to discuss issues of maltreatment gives them the power to act as gatekeepers to stop children from participating in research. Therefore, researchers should contemplate if parental consent should be waived and how research can be developed to mobilise children's agency and ensure their meaningful cooperation in researching different aspects of violence that affect them. This chapter presents and critically analyses different research examples and discusses their ethical dimensions from a children's rights perspective. The research questions start with discussing the utility of consulting children in research on maltreatment; the gatekeeping role of caregivers; the distress and harm eventually caused to children and young people by participation in research and the benefits of participation for children. The survey examples discussed lead to the conclusions that research on maltreatment might sometimes cause distress; caregivers' power to refuse consent for their children's participation in research on maltreatment can alter epidemiologic data and impede children's right to express their opinion on issues that are central to their lives and therefore, it should be waived; consulting children is essential for

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Participatory Research on Child Maltreatment with Children and Adult Survivors, 65–81
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collecting data on and improving responses to child maltreatment; and children's contribution to research on maltreatment depends on the adopted methodologies of the research, more advanced forms of participation, and training children to express their opinions, thus enriching scientific knowledge and promoting change.

Keywords: Child participation; children's voices; parental gatekeeping; ethical dilemmas; sensitive research; empowering children

Introduction

Data collection on maltreatment of children in their homes; by their parents and caretakers; on school premises or in institutions; and via cyberviolence, domestic violence, community violence or peer violence are considered sensitive research topics and covered by ethics regulations. This chapter discusses key ethical considerations of research on child maltreatment, analysing examples of studies that gave children the opportunity to have their voices heard and contribute to the accumulation of knowledge with empowered voices.

Although participation of children in research becomes more and more solidly grounded ethically and methodologically, its translation in the practice and service evaluation in child protection is limited and often does not cover the most disadvantaged children (Lätsch et al., 2023; Toros et al., 2021). Children's participation in research on maltreatment is justified by the social value of their contribution to the accumulation of knowledge, which is meant to affect child protection policies, improving responses to cases of maltreatment and prevention measures. The main dilemmas for involving children and young people in research on child abuse, neglect and connected adverse experiences revolve around the importance of listening to children's views on these topics, their vulnerability and the need to protect them against the distress and trauma of investigating such topics (Bradbury-Jones et al., 2018; Gordon, 2020). From a bio-ethical-medical stance and according to the ethics regulations presented in Chapter 3, children and young people are considered less capable than adults to express their opinions and understand all implications of the research targeting them (Canadian Paediatric Society, 2008; Council for International Organizations of Medical Sciences, 2016 [CIOMS]; World Medical Association, 1964/2018). In a traditional view, children younger than the age of maturity are considered less capable than adults to understand research procedures and make decisions according to their best interest; therefore, for children, the risks of taking part in research are greater than the benefits (Mathews et al., 2022). Accordingly, children are seen as having a limited capacity to give informed consent or commit to research with the same degree of awareness as adults (Daley, 2013; Lohmeyer, 2019). On the other side, from a children's rights view, children are autonomous and agentic people (Blanchet-Cohen, 2009; Larkins et al., 2021) with the right to express their views. Therefore, in discussing ethical concerns of research involving children while pursuing their best interest, their vulnerability and agency are both relevant (though not the only) ethical concerns that need to be addressed. Further concepts discussed in this chapter are marginalisation and silencing of children's voices, empowerment and power given to children, and inclusion and influence, as discussed in a literature review on participation of vulnerable children in research by Bradbury-Jones et al. (2018).

Ethical Concerns in Research With Children From a Historical Perspective

Researchers who are confronted today with the complicated ethical procedures for including minors – considered a vulnerable category compared to adults (CIOMS, 2016) – need to understand the controversial legacy of research with children of the previous century (Mudaly & Goddard, 2009). Such research took place in some well-established medical schools and education and psychology research centres before, during and after World War II. For example, in the classical experiment in 1920 with Little Albert,[1] a 9-month-old baby, designed by the founder of behavioural psychology, J. Watson, to prove that fright is a learnt behavioural reaction that can be conditioned, the single-case experiment involved an orphaned child.

The criminal experiments of Nazi physicians on people, including children,[2] are most widely known, and their condemnation was well documented during the Nuremberg medical trial. Despite the first code of ethics (Nuremberg Code of 1949) that condemned research that causes harm to people and required consent of research participants, medical experiments risking children's lives were conducted and even praised, including in the Western democracies during the second half of the last century, in the name of the greater cause served by the research. For example, from 1956 to 1970, Krugman identified the A and B forms of the hepatitis virus by experimenting with virus samples on children with mental disabilities from disadvantaged families. Children were subjected to highly risky procedures by taking advantage of the parents' hopes to place children in a special school, without having clear knowledge of the health risks for their offspring (Murphy, 2003). In the same logic of good intentions, governed by the best of anti-racist intentions and undeniably successful in demonstrating how racist ideas can manipulate children, Jane Elliott designed and replicated numerous times her 'blue eyes–brown eyes' educational classroom experiment (Bloom, 2005, 2021). Taking place in the context of the murder of Martin Luther King, Jr. in 1968, this educational research project was meant to demonstrate how arbitrary criteria can

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[1] This is a classic experiment for behavioural psychology presented on numerous websites and psychology manuals, such as https://www.simplypsychology.org/little-albert.html (see Watson & Rayner, 1920).

[2] At the Nuremberg trial, 70 cruel medical projects were documented, and 23 Nazi physicians and scientists, who were responsible for victimising at least 70,000 individuals through their experiments, were tried. Several children (numerous twins) were victims of Mengele and his fellow physicians. See the webpage of the U.S. Holocaust Museum: https://www.ushmm.org/collections/bibliography/medical-experiments.

generate prejudices. In her capacity of being a teacher in an all-Caucasian rural Iowa elementary school, Elliott divided her class in two groups and explained that the blue-eyed students were genetically superior to the brown-eyed ones. Although she recognised the pain and suffering caused to her participants, she did not stop her experiment, counting on the debriefing session to restore children's cooperative relations and acknowledge the wrongdoing of discrimination. Although this educational experiment had strong experiential learning value, it has become an example of ethical misconduct, exposing unaware children to feeling unworthy, compared to others, and ignoring the risks to their well-being.

To avoid harm to children in research processes, international and national ethics codes and medical and social science research bodies have placed children's best interest at the forefront of the ethical assessment of the value of research, defining guidelines for the child's consent to take part in a study. As explained in Chapter 3, firm procedures and guidelines for research with children have been developed in all countries, though debates on the meaning of children's and adolescents' best interest, vulnerability, legal and developmental capacity to understand the information about the research process conveyed to them, and the consequences for their life and mental state have not yet reached a common and unique answer among different forums and countries. As a general idea, CIOMS (2016) has endorsed children and adolescents' involvement in research, unless there are strong arguments for exclusion due to risks. International and national research ethics bodies have the mandate to approve and fund research with children and adolescents, if seen as contributing to scientific progress, having practical benefits, serving the best interest of participants, and protecting them against all harm throughout the research process. According to regulations, considering children's vulnerability, parents or those acting in loco parentis need to act as gatekeepers for children's participation in research and give their consent for their children who are not of a certain age considered as developmentally appropriate for understanding the consequences of research.

For the ethical assessment of research designs regarding child maltreatment involving children, the main issues are the utility of research for the participating children and youth, their families, their communities, and the institutions and services that respond to violence against children regarding knowledge development; types of vulnerabilities (categorical, individual, group, or contextual) and the risks associated with them (Gordon, 2020; World Medical Association, 1964/2018); probability and level of harm or discomfort experienced during and after the research (CIOMS, 2016; Cohen et al., 2018; Mathews et al., 2022; Santelli et al., 2003); protection of data for privacy and confidentiality (National Bioethics Advisory Commission, 2001); level of involvement of children in research and handling of power relations between adults and children involved in research (Kyegombe et al., 2019; Larkins et al., 2021); and necessary procedures of informed consent and gatekeeping by parents or caregiving adults or the waiving of consent by legal guardian (CIOMS, 2016; Kyegombe et al., 2019; Priebe et al., 2010).

Methodology

The objective of this study is to reveal ethical issues raised by children's participation in research on maltreatment by scrutinising examples based on different methodologies like single-case experiments, population surveys, interviews, and participatory action research. Based on the literature review by Bradbury-Jones et al. (2018), the research examples analysed in this study were selected for their relevance to the following ethical topics: (a) children seen as a vulnerable population that can be exposed to risks of harm by researchers; (b) children can have their agency barred due to gatekeeping by parents or caretakers or needing parental consent to be allowed to have their voices heard; (c) violence is considered a sensitive issue, with children facing risks when involved in research on this topic; (d) children have an opinion on topics such as violence, which they might also face in real life; and (e) children's agency and ability to act based on what they learn from research are valued.

All these ethical issues are often interrelated in studies that explore child abuse and neglect or any other form of violence, because they touch on intimate adult–child relationships or family relationships, especially the intimacy of the child involved in research. In fact, violence against minors represents a sensitive issue not only for children and young people involved in such research, but also for their families, educators or any other caretaker who needs to give consent for them and for the schools, child protection agencies and communities that are supposed to monitor children's safety. Thus, the sensitivity of the topic of such research leaves its mark on the caretaker's role in gatekeeping children's participation in research.

These issues led to the following research questions related to ethical issues:

(1) Does consulting children in research on maltreatment contribute to the development of policies and practices in this domain?
(2) Knowing the sensitivity of the topic for parents and other caregivers, should they be the gatekeepers for their children's participation in research on maltreatment?
(3) Does research on maltreatment cause distress and harm to participating children?
(4) What are the benefits of children's participation as co-researchers?

Ethical Issues Illustrated in Examples of Participatory Research With Children on Maltreatment

The views about children as a vulnerable category of population needing protection from not only violence but also being questioned about this sensitive issue have been challenged by researchers, who saw the merits of giving children more roles in the production of scientific knowledge. The issue of participation of child victims in child protection decision-making and in research evaluating child protection processes has generated ongoing debates (Lätsch et al., 2023; Tisdall, 2017). Recognising children as knowledgeable agents while admitting the specificities of their age-limited capabilities has contributed to increased variety of research methods. Besides using interviewing, surveying and observing to explore topics related to violence against children, multi-method 'mosaic approaches' have been developed, like the use of visual media, telephone and online enquiries, photography and photovoice, roleplaying, theatre forums and community mapping, which allowed greater flexibility in the relationship of the researcher with the children and thus, allowing children more agency (Clark & Moss, 2011; Diaconescu & László, 2016; Fargas Malet et al., 2010). The following sections explore a few such examples in search of a better understanding of children's contribution to understanding and responding to different forms of child maltreatment.

Does Consulting Children in Research on Maltreatment Contribute to Enhancement of the Knowledge Base in This Area and the Development of Policies and Practices?

The usefulness of including children in participatory research and the opportunities they could have in this process can be exemplified by a comprehensive worldwide United Nations study on violence (Pinheiro, 2006), which involved around 8,000 children from all continents through interviews, focus groups, online surveys, regional consultations and forums. Acknowledging that violence against children is a major threat to global development in the new millennium, the World Report on Violence collected accounts of children in their homes and families, schools, care facilities, justice institutions, work settings and neighbourhoods. The analysis of national and regional reports indicated the severity of abuses and threats faced by children due to physical punishment, sexual abuse and neglect, amplified by war, poverty, migration, injustice and discrimination with dimensions and severity that reached epidemic proportions (Lenzer, 2015). The study prioritised children's involvement in research, collecting a wealth of accounts from them and including them in presenting the reports, to make their voices heard by policymakers. This resulted in unveiling violence by child participants in discussions groups and policy forums, making 'invisible' phenomena much more visible and comprehensible for the public, professionals and policymakers. Considered an example of large participatory research on violence, the report stated that 'children have the rights to express their views, and to have these views taken into account in the implementation of policies and programs' (Pinheiro, 2006, p. 17). Following up on this recommendation, the Global Status Report on Preventing Violence Against Children (WHO, 2020) emphasised the need to consult with children, viewing them as competent partners in the protection against and prevention of violence.

Asking for Parental Consent and Gatekeeping by Parents

Getting clear, consistent and comparable prevalence data on different forms of violence against children with the help of population surveys, including large samples representing all segments of the population and regions, is still very challenging for the research community. Maintaining parental consent as a compulsory procedure for research and the high rates of parental refusal are often fuelled by protectionist attitudes, considering that questions related to physical, psychological and sexual abuse result in distress and aversion of children. Controversies related to children's capacity to be reliable informants for prevalence surveys on maltreatment in homes and families are unavoidable for research with children. Therefore, it is important to acknowledge that offering parents the option to decline children's participation in research – thus ignoring the conflict of interest between parents (or caretakers) being in a position of power and their children who depend on them – has the effect of silencing children with maltreatment experiences in the family. In this way, these parents become gatekeepers and deny children's right to participate in research, strengthening the taboo aspects of talking about family dynamics and eventual violence to people or professionals outside the family.

If the proportion of parents denying children's involvement in large surveys significantly increases, maltreatment prevalence rates obtained with the most statistically reliable and valid instruments might become questionable. Based on Romanian BECAN[3] research data (Antal et al., 2012; Roth et al., 2013), after inviting parents of 5,858 pupils to allow their children to complete a questionnaire on the topic of 'parental relationships and child rearing practices', the refusal rate by parents reached 29.1% for 11-year-olds and 26.5% for 13-year-olds (with an average of 27.8%). In some schools and areas, the refusal rate was more than one third, even reaching 40%. These high refusal rates were obtained despite adopting a passive parental consent procedure for children. For children who would disclose parental maltreatment or need support to manage distress related to questions in the survey, field researchers received many guidelines for safeguarding.[4] Procedures included information sheets for both parents and children about data confidentiality and anonymity and participants' rights to withdraw from the research if they did not want to continue. The detailed methodological, data protection and ethical provisions were described by Roth

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[3] The Balcan Epidemiologic Child Abuse and Neglect Research (BECAN) project was funded by European Union's 7th Framework for Research and Innovation (223478/HEALTH/2007) and coordinated by the Institute of Child Health in Athens, Greece. Its aim was to collect data on child abuse and neglect in families in nine European countries: Albania, Bosnia, Bulgaria, Croatia, Greece, Republic of North Makedonia, Romania, Serbia and Turkey.

[4] In the BECAN research report, safeguarding issues are described in detail. Any indications of being at risk of maltreatment were followed up by field researchers. Interdiction of parents to allow children to complete the survey was respected (Roth et al., 2013; Voicu et al., 2016).

et al. (2013) and Voicu et al. (2016). In contrast to parents, children's assent forms were declined by less than 1% of children in the 11–13 age range (0.21% for 11-year-olds and 0.28% for 13-year-olds). Adolescents older than 16 did not need parental consent and their consent refusal rate was 1.05%, showing their eagerness to express their views.

To understand more about parental reasons for gatekeeping, researchers analysed the phone and email messages received from parents who used the researchers' contact information from the information leaflets. The messages sent to researchers showed that receiving information leaflets and consent forms for responding to a research invitation – addressed both to them as caregivers and to their children – was new and unusual for Romanian parents because previously there had been very few social or psychological research projects that required parental consent. This has been mostly a procedure for medical experimental research. So, the procedure triggered the imagination of some parents, generating suspicions that rapidly snowballed in the school community. Despite the information offered, many parents had difficulty understanding the procedures ('I discussed with other parents, and we do not understand what is asked from our children and from us'; 'Are you taking our children somewhere for questioning?'; 'Where will the survey take place?'). A dozen parents objected to the surveys due to questions about parenting methods, abuse and especially sexual abuse, and they expressed doubts that the research had been approved by 'authorities'. From the conversations, we learnt that the information letter must feature more exact data on the procedures and timing of the survey; concrete information given to children is not enough for parents. Whenever possible, the field researchers met with groups of parents to convey the exact information and dissipate their concerns. But the sensitivity of the topic of violence against children could not be eliminated nor could such meetings change the conservative attitudes that children's participation in surveys on family relations might encourage them to rebel against parental authority.

Distress, Risks and Harm in Research on Maltreatment (Focussing on Sexual Abuse)

Despite progress in understanding the agency and relative autonomy of children and young people and granting them space to express their opinions, there is still a reluctance of institutional ethics boards and national or professional ethics bodies to wave parental consent for such projects for children and even adolescents. The motives are often based on 'inaccurate assumptions about risks and harms to participants', 'the indiscriminate labelling of children as a vulnerable group', and 'the over-cautious position regarding trauma research in general' (Mathews et al., 2022, p. 3). Given these controversies, studies on sensitive issues such as sexuality, sexual abuse and violence are necessary because they can offer important clues on how children might be harmed or avoid distress due to research. Priebe et al. (2010) conducted such a study, measuring the negative emotions noted by research participants in Sweden or Estonia in connection with their participation in the survey. As mentioned by the authors, the expressed feelings of distress or discomfort were situational and comparable to emotions of everyday life (Priebe et al., 2010). The results of the study showed that most adolescents did not agree with statements on emotional discomfort while answering questions related to sexual abuse.[5] Using path model analysis, the study found that reports of penetration did not significantly explain discomfort; sexual inexperience of respondents and high ratings regarding the belief that rape is a myth had a stronger explanatory power for discomfort. For the issues of risks of harm discussed in this chapter, this means that being sexually abused was not directly related to discomfort experienced during research. According to this study, the adolescents' risks of responding to the survey were not higher than usual everyday risks.

The attitude of children towards answering surveys related to child physical, psychological and sexual abuse and neglect were examined in a qualitative, participatory way using focus groups with respondents aged 11, 13 and 16 years using the ICAST instrument, based on BECAN study in Romania (Roth et al., 2013). Assuming that asking consent from parents is less about children's competences and more about cultural reluctance to take children seriously (Alderson & Morrow, 2011; Morrow, 2009), the researchers wanted to hear from children about what it means to respond to surveys on sensitive topics. The procedure adopted for this purpose was a two-phase process: First, we asked children to complete the ICAST-C survey, then we asked them to participate in a follow-up focus-group discussion, keeping the three age groups separate. Looking into the dilemmas around children's immaturity to make decisions about participating in surveys on sensitive topics like violence, including sexual violence, children were invited to debrief after completing the survey and give their advice on how such surveys should be best carried out from their point of view. Because children often do not get credit for being competent enough to answer surveys, one question referred to whether participants felt competent to fill in the survey. Another question referred to making decisions about consent, asking if children thought parents should decide if their offspring could participate in research.

The members of the two younger age groups received parental consent before they were invited to consent to completing the survey and participating in focus groups. Children completing the surveys did not show any kind of distress during the research. The oldest participants in the focus group, 13 and 16 years old, considered that children their age should be able to participate in such surveys without their parents' consent because the questions were about topics familiar to them. Young people indicated that questions on parenting methods gave them the opportunity to reflect on their family relations, and the researchers noted that one girl (aged 16) mentioned thinking about her future parenting. These two age groups considered that for participants their age, all questions were

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[5] According to the study, many adolescents strongly disagreed with items such as: 'the questions were unpleasant to answer' (63%); 'one should not ask people such questions' (77%); 'the questions can have unfortunate impacts' (68%) and 'the questions were too private' (63%). Between 10% and 18% agreed with these statements. Country-level differences between Sweden and Estonia were noted in this study on rape myth acceptance.

comprehensible, including those asking about their sexual experiences. For these issues, they warned researchers against using such questions with younger children, indicating that parental consent would be necessary if questionnaires included these questions. The discussion with the 11-year-olds revealed that some of them felt the need to have parental advice before making decisions on consent to participate in such research. Overall, the youngest group favoured the idea of making the decision themselves, but preferably after having the opportunity to consult with their parents. The results indicated that children are eager to take part in surveys on the topic of family relationships and violence, although doubt about the capacity of younger children to make these decisions appeared to be internalised by the adolescents. The need of children, mostly from the younger group (11 years old), to get advice – not approval – from parents about participating in such a survey seems an expression of children's need for parental encouragement to freely express their opinions on family relations. Based on attachment theory, for some children who experienced violence, talking about parenting methods might be difficult because it involves contradictory emotions and risks or seems a betrayal of the person towards whom they feel ambivalent, both loving and being angry at them. Kilkelly and Donnelly (2011) reported similar results, also noticing that children's opinions were ambiguous: They not only want to be listened to but also need to feel supported in their opinions. Therefore, an ethical requirement in research on violence should be that field researchers understand children's ambivalence in their attitudes and offer them support in expressing their often contradictory feelings.

Benefits of Children's Participation as Co-Researchers

Professionals' knowledge about different forms of child maltreatment and the services dedicated to respond to victims are increasingly shaped and informed by children's views (Mathews et al., 2022; Nowland et al., 2022). Researchers need to be aware of how children conceptualise violence and how they might differ from adults in their definitions (Kosher & Ben-Arieh, 2020). Methodologies have been developed to invite children affected by adversities in their communities or by abuse or neglect to plan and evaluate programmes and services (Nowland et al., 2022). Children's opinions and programme evaluations often challenge the opinions of experts (Bradbury-Jones et al., 2018). In the Participation for Protection European project,[6] researchers from six countries explored children's concepts of violence, protection and support against violence, engaging 91 children (9–10 years old) and young people (15–16 years old) in 14 working groups and 1,272 school children, to answer a survey. The objective of the project was to

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[6] Participation for Protection was funded by the European Union (P4P 2018-2020 REC-CHILD-AG-2016-01); led by Queens University, Belfast; and involved Austria, Belgium, Germany, Northern Ireland, Republic of Ireland and Romania. Information about the project can be found online: https://www.qub.ac.uk/sites/participation-for-protection/.

understand children's views on forms of maltreatment and child protection issues and integrate children's voices in child protection training. The project followed the Lundy model (Lundy et al., 2011), which defines child participation by four essential components: children should have a voice, they should have a safe space to express themselves, there should be an audience to listen to what they have to say and their opinions should be taken into consideration such that they influence adults involved in children and childhood policies. To design training materials for professionals, researchers initiated working groups with children in the participating countries in the following settings: residential institutions, situations of migration, Roma children in disadvantaged Roma communities and closed residential facilities. Advisory groups of children and young people guided researchers in formulating the questions on topics commonly agreed on: how they defined different forms of violence, what kind of risks they perceived, what kind of help they expected, why children and young people might not ask for help, the best ways people their age should ask for advice and support if they are harmed, to what kind of helper they would turn etc. Based on their age differences, children and young people worked in separate groups and participated in all phases of research, designing, debating and piloting the items of the survey and voicing arguments in favour of their opinions. Teaching materials that included data and quotes from children's survey, focus groups and interview responses were much appreciated by social work trainees and teachers attending modules on children's rights and child protection. Thus, the usefulness of the research was proved by the success of the training, and the evaluation sheets showed great satisfaction (McAlister, 2020). This successful example of child participation in research was possible due to thorough planning around research ethics and handling of eventual risks of children being affected by taking part in the advisory and working groups.

All participating children and adolescents were offered training sessions to inform them about the scope, length, methods and other details of the research project. Adult facilitators explained the rights of participants in the research process, including the right to not participate or to leave the project at any time. Due to the preparatory training activities and discussions during sessions with the researchers, both the participants in the two advisory groups and those in working groups became more knowledgeable about protection against violence and the accessibility of child protection services. Leaflets were distributed to all participants with child-friendly information on violence and what services are available for them in case they experienced violence or cared for the safety of others. Information on support for victims of violence was contextualised and discussed for each country. Facilitators created a respectful and inclusive climate for discussions, giving special attention to the dynamics in the working groups with vulnerable children (centre for migration, shelter for trafficked children, residential care, LGBT children, Roma and Traveller children in disadvantaged communities, victims of domestic and political violence).

Attendance was constant for the eight children aged 9–10, but less good for the adolescents, whose enthusiasm was high at the beginning, when specific tasks were given, but fluctuated during the process. In all phases of the research, children's and young people's feedback indicated that they felt interested in the topic and empowered by the process. Children felt valued ('what we are saying impacted the process'); they also commented on how they managed to keep the language of the research child-centred, asking questions in case they had difficulty understanding the researchers; and the schools of children responding to the surveys made signposting leaflets available for all their students.

Including children's voices in the teaching materials was much appreciated by training participants. In the evaluation forms, a trainee from Germany stated that hearing children's voices gave her more confidence in her actions; for another, it was more convincing because the knowledge came directly from children; a third expressed much appreciation about the messages coming directly from children and not statistics from the books; and a fourth one reported feeling positive because the learning process was built around children's voices.

The level of participation of children in research on family, peer or community violence largely depends not only on the conception of the researchers of children as autonomous beings but also on the methodology chosen to empower participating children to express themselves. 'Young people popularly symbolise a source of hope and social change' and can act 'capable and responsible, whilst also needing protection or being a risk to others' (Lohmeyer, 2019, p. 42). Adult researchers who rely on children's agency and empower them to become co-researchers can benefit from children's engagement and enthusiasm or encourage them to conduct their own research as peer researchers (Larkins et al., 2021) on topics that are important to them.

Discussion

Ethical issues related to children's participation in research on violence are strongly linked with the principles of children's rights as formulated in the Convention on the Rights of the Child, adopted by the United Nations (1989), and the numerous comments and other documents that followed on the best interests of children, non-discrimination, respect and confidentiality towards children, listening to them and helping them express their attitudes, protecting them, and preventing violence and providing resources to respond to violence if it occurs. Reviewing these ethical issues with practical examples of quantitative and qualitative research with children showed the utility of listening to them in a respectful way, so that children feel their opinion matters and that they are worth consulting, in the same way as any adult, without subjecting them to any forms of risks of violence or exploitation.

Acknowledging the vulnerability of children facing adults in position of power and the developmental limits of children's and young people's capacity to understand research requires that researchers do all they can to protect underage participants against any form of harm or distress and develop safeguarding procedures (Mathews et al., 2022). The recognition of children's vulnerability does not exclude recognising their capabilities to reflect on the help they need and the dangers they may face. As formulated by Lundy et al. (2011), the United

Nations Convention on the Rights of the Child has been an essential lever for creating methodologies to include children as participants or even co-researchers in studies that concern their lives. Participation in research as a right to exercise autonomy means that children are considered rights holders, capable of forming an opinion and exercising their freedom of expression, including intimate topics like their relationship with people in positions of power and attachment figures. It also means they have the right to express their views on the treatment they receive in care services and from professionals who are supposed to provide support; it means they are entitled to be included in planning prevention approaches. Many participatory research projects are not limited to the collection of data but intend to inform services or policies. Research can create a reflective, stimulating and change-oriented learning environment – and can take a critical stance (Bereményi et al., 2017; Larkins et al., 2021).

Lastly, the right to provision means children are also entitled to receive support that serves their best interests, whether they need justice or treatment for the trauma they suffered, health care interventions, or supportive actions (offline and online prevention programs, targeted community interventions, shelters, help lines, campaigns etc.) to reduce the risks of maltreatment in their families, schools and communities.

Conclusion

Responding to the research questions, the analysis of research examples has demonstrated the following.

Consulting children is essential for collecting data on child maltreatment. Children's contribution depends on the adopted methodologies of the research; more advanced forms of participation – following methods where children are trained to express their voices – generated more benefits for both the accumulation of knowledge and promoting changes in the response to and prevention of violence against children (Blanchet-Cohen, 2009; Larkins & Bilson, 2016; Office of the Special Representative of the Secretary-General on Violence against Children, 2020).

Examining parents' consent rates regarding their children's inclusion in large population surveys indicated that parents tend to exercise their gatekeeping role and keep children and adolescents away from expressing their views on parent–child relationships. This is likely due to reasons of protecting their offspring from being confronted with sensitive issues like different forms of abuse and neglect, including sexual abuse; fear that participation in research would encourage them to rebel against parental authority; their lack of understanding of survey procedures or simply to avoid children's disclosure of being exposed to violence in the family. High parental rates of refusing children's participation in research contrasted with children's willingness to participate, which was almost unanimous in the discussed BECAN research (Antal et al., 2012; Roth et al., 2013). Thus, caregivers' power to decline consent for their children's participation in research on maltreatment can alter epidemiologic data and impede children's right to express their opinion on issues that are central to their lives and, therefore, should be waived as recommended by CIOMS (2016).

As mentioned in the literature and shown in the survey examples discussed in this study, research on maltreatment did sometimes – though not often – cause distress to participating children. But the feelings of research participants were situational and comparable to emotions of distress in their everyday lives (Priebe et al., 2010). Due to the sensitivity of research on maltreatment, the analysis revealed that children need a supportive attitude and clear protective procedures from the researchers (Priebe et al., 2010; Roth et al., 2013).

Despite these challenges, research can also bring benefits for children and young people. If used appropriately, participatory methods can contribute to recalibrating children's understanding of the implications of maltreatment on their lives. Thus, participatory research is beneficial for children and young people involved in research on violence by building participatory spaces where they can get the attention they need and learn skills to promote changes in their environments (Bradbury-Jones et al., 2018; Larkins & Bilson, 2016; McAlister, 2020). If their participation in research felt meaningful and contributed to change, children and young people reported more benefits for them and their peers: becoming more active and showing leadership (75.0%), followed by academic (more entrusted in school) or career benefits (55.8%), social benefits (36.5%), interpersonal skills (34.6%) and more confidence in their intellectual capacities (23.1%; Anyon et al., 2018).

Regarding the controversies about whether children and young people are aware of the risks they might encounter and whether they can express their needs in their relationships with the adults who are supposed to protect them, the research examples consistently demonstrated that the mentioned topics are part of their lives, they are interested in and can reflect on them and they are ready to share their opinions. More scoping reviews and meta-analysis are needed to generate further evidence that could convince the international research community that children and young people, although not fully mature from a legal point of view, are autonomous enough to decide freely if they want to participate in research on violence and that gatekeeping by parents or caregivers might counter children's best interest and their right to express themselves and could even alter research results.

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Chapter 5

Cultural Factors Affecting the Participation in Research of Children Victims of Child Abuse and Neglect: The Case of Turkey

Nilüfer Koçtürk, Sinem Cankardaş, Zeynep Sofuoğlu and Betül Ulukol

Abstract

Culture significantly influences individuals' lives and shapes their behaviour in an ecological framework. In this chapter, we examine the issue of children's participation in research about child abuse and neglect (CAN) in the context of Turkey – a country that bridges the Asian and European continents. This study was based on a review examining studies on CAN in Turkey. Thus, the main goal was to find cultural explanations for the scarcity of participatory research with children in the field of child maltreatment. A review examining studies on CAN in Turkey found that no study included children victims of CAN or explored why children victims of CAN have not been participating in research. Therefore, we analysed ecological factors influencing the participation of children in CAN studies and interpreted the findings based on our observations as experts in this field. The analysis indicated that causes are not only due the characteristics of the caregivers and children but also result from the interaction of various environmental and systemic factors. Recommendations for politicians and researchers to increase children's participation in research are discussed.

Keywords: Turkey; ecological system approach; cultural factors; child abuse and neglect; values; family

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Introduction

Child abuse and neglect (CAN) is a critical social problem affecting an individual's childhood and adult life (Dobson et al., 2021; Levin & Liu, 2021). To address the problem of CAN in terms of both treatment and prevention, we need to know the prevalence and extent of the problem (Sumner et al., 2015). The creation of policies for families and children, employment of experts working in the field of child protection and services for children and families depend on understanding the mechanisms and estimating the prevalence of CAN.

The literature shows that millions of children around the world are exposed to maltreatment (Mathews et al., 2020; Stoltenborgh et al., 2013a, 2013b). However, in many countries, the extent of CAN is not clearly known, and many nations lack reliable comparative national prevalence data (Mathews et al., 2020; Sumner et al., 2015). This is relevant, particularly for undeveloped countries. According to meta-analyses by Stoltenborgh et al. (2013a, 2013b) and Jud et al. (2016), prevalence rates of CAN are primarily based on data from developed countries, and few studies have focused on underdeveloped or developing countries. Although the rates in developed countries are worrisome, they are much higher in underdeveloped or developing countries (Klevens & Ports, 2017; Stoltenborgh et al., 2013b).

In this chapter, we examine the issue of children's participation in research about CAN in the context of Turkey – a country that bridges the Asian and European continents. Turkey's unique cultural characteristics are unlike European countries or other Muslim countries (Sunar & Fişek, 2005). Legally, it adopts the concept of a secular state and has citizens of different nationalities and religions, although many residents are Muslims (Sunar & Fişek, 2005). Due to this mosaic structure of the country, the child's position in the family and right to participate in research may vary among ethnic cultures (Coşgun, 2019; Güçlü, 2016). In addition, the position of the child in the family in Turkey is affected by many factors, such as the structure of the family (extended or nuclear), sociocultural status, place of residence and political and religious views of parents (Güçlü, 2016; Taşkın, 2009). In the traditional family type, hierarchical and asymmetrical family relations among father, mother and child are nourished by strict religious and social teachings (Günaydın & Aşan, 2017). In rural areas, a traditionalist perspective often persists in family structures if the parents' education level is low or the parents do not adopt a secular perspective (Güçlü, 2016). Women and children are expected to submit to authority in these family structures, and fathers and other men are seen as authority figures (Koçtürk, 2021; Sunar & Fişek, 2005). The traditional view of children as dependent on parental authority might also be reflected in how research on family relationships, CAN and gendered violence is conducted. Due to urbanisation and the transition from traditional to nuclear family structures, the balance of authority in the family has begun to differentiate; these changes in family structures have led to more democratic parental attitudes of family members towards children (Güçlü, 2016). In family structures where the mother is involved in working life (Ayyıldız, 2005) and a secular perspective is adopted, the position of the child is valued and a more democratic parenting approach is adopted (Günaydın & Aşan, 2017; Sunar & Fişek, 2005). In other words, the child's position in the family is evaluated in parallel with the mother's position (Koçtürk, 2021). As urbanisation, parents' education level and egalitarian perspectives towards gender equality advance, both family relations and shared authority change, alongside changes in the family position of the child (Coşgun, 2019; Güçlü, 2016). In this book chapter on factors affecting children's participation in research, we focus on the problem in the context of the dominant culture, which is characterised as collectivist and patriarchal.

Children in Turkey are less involved in CAN research (Uslu & Kapçı, 2014). For example, a report that systematically evaluated relevant studies in Turkey emphasised the limited number of studies on the prevalence of child sexual abuse and that child participation is at a low level (Uslu & Kapçı, 2014). Indeed, there is no national database for CAN victims in Turkey; few studies have been conducted with internationally accepted measures and, therefore, data are not comparable internationally (Eratay, 2000). In the Child Abuse and Domestic Violence Research in Turkey study by UNICEF (2010), the prevalence of emotional abuse was 51%, physical abuse was 43% and sexual abuse was 3% in a sample of 1,886 children aged 7–18. In a survey in eight Eastern European countries, among 1,763 children, the physical abuse rate was 14.6%, domestic violence witnessing was 17.9%, emotional neglect was 8.7%, emotional abuse was 3.7% and sexual abuse was 6.9% (Bellis et al., 2014). Methodological problems like differences in the definition of CAN have led to different results among different samples and regions and the inability to compare these results (Koçtürk, 2019). In most studies, data have been obtained from parents or retrospectively from adults (Uslu & Kapçı, 2014), indicating that cultural issues influence how research in CAN is implemented.

This chapter focuses on the impact of cultural factors on children's participation in research. Using ecological theory as the conceptual framework, we examine the effect of cultural barriers to conducting research with children, particularly myths about CAN. The concept of cultural factors affecting children's participation in research, as the term suggests, refers to a psychosocial context. Moreover, this issue, which involves individuals younger than 18 years old, is not independent of their social environment, especially their parents. From a theoretical point of view, this opinion is compatible with the ecological system approach. Although this approach provides a holistic, context-specific and multilevel perspective on CAN (Martinello, 2020), it can also guide researchers and experts in identifying and finding solutions to the problem of why fewer children who are victims of CAN are involved in research. For these reasons, this book chapter primarily provides information on the ecological system approach and the micro and macro barriers and factors that affect children's participation in research. In this framework, this book chapter deals with the difficulties experienced in the legal processes for conducting research with children in Turkey, myths about CAN in society, fear of stigmatisation of children and their families and other systemic problems from an ecological perspective. Finally, recommendations for politicians and researchers to increase children's participation in research are made.

Conceptual Perspective: Ecological System Approach

According to the ecological point of view (Belsky, 1980; Bronfenbrenner, 1979; Rosa & Tudge, 2013), the formation of a behaviour is affected by various systems in which the individual exists and their interactions with others; in other words, it is based on a multifactorial etiology. According to Bronfenbrenner (1979), human development occurs through progressively more complex reciprocal interaction between an actively evolving biopsychological person and the people, objects and symbols in their immediate environment (Eriksson et al., 2018; Rosa & Tudge, 2013). In other words, according to this theory, when the environmental conditions with which a child interacts directly (e.g. family) or indirectly (e.g. parent–school collaboration) are appropriate, the probability of realising their inherited traits and potential increases (Bronfenbrenner, 1979). Bronfenbrenner (1979) emphasised four systems with this concept of context: microsystem, mesosystem, exosystem and macrosystem.

The microsystem is the most proximal setting where a developing person can interact face-to-face with physical environments such as home, childcare, playground and workplace (Rosa & Tudge, 2013). Regarding the CAN phenomenon, four microsystems typically surround children: experiences in the family, with teachers, with peers and in the school environment (Lee, 2011).

The mesosystem is the relationship between two or more microsystems in which the developing person actively participates (Rosa & Tudge, 2013). In the context of CAN, the mesosystem refers to interactions between the child's systems, such as those between the child's family and the perpetrator and between the child's teachers and family (Rosa & Tudge, 2013).

The exosystem is an environment in which the developing child does not participate actively but still experiences its influence in their life – for example, school curricula and popular media (Martinello, 2020; Rosa & Tudge, 2013). In the context of CAN, the difficulty of working conditions for parents is an example of this system (Maguire-Jack et al., 2022).

The macrosystem involves the core beliefs, values, cultural attitudes and ideologies such as those of the economic, social, educational, legal and political systems that affect the child's culture and society at a broader level (Martinello, 2020; Rosa & Tudge, 2013). We see the impact of the macrosystem on other ecological environments through its reflection on the functioning of subsystems (e.g. family, school).

Methods

This study involved a review of studies on CAN in Turkey. Articles and theses were searched in the National Thesis Center Database (Council of Higher Education – Thesis), Ulakbim, and Web of Science databases between November and December 2022 using the following keywords: 'child abuse' *and/or* 'child neglect' *and* 'child participation.' Although more than 20,000 studies were identified in the first stage, when the search was limited to the scope of the research question, the research team did not find any article directly looking for reasons why victims of CAN have not participated in research. Therefore, the research question was adjusted to look for cultural factors acting as barriers and hindering children's participation in CAN studies in Turkey, along with factors that enable their participation, in the various ecological systems described in Bronfenbrenner's theoretical framework.

Ecological Factors Influencing Participation of Children in Research

Adopting Bronfebrenner's (1979) conceptual framework, we argue that to understand and increase the participation of child victims of CAN in research, we need to understand values, principles, traditions, norms and regulations intertwined in the process–person–context–time model. Thus, we analysed the Turkish literature on CAN, looking for possible cultural barriers and enabling factors at all levels of the ecological system: microsystem, mesosystem, exosystem and macrosystem.

Microsystem

To gain direct access to children who are victims of CAN, it is necessary to be in environments such as family and school, which are included in the microsystem of children. However, even professionals providing services to children in Turkey, before conducting any research with children or asking for the child's participation request, must obtain permission from the parents. In other words, it is not possible for children to participate in research without the permission of the child's parents. According to the Patient Rights Regulation (1998), the law obligates researchers to get parents' informed consent for their child's participation before consent can be obtained from the children. Factors that may affect children's participation in research in the scope of microsystem include the following:

- Family structure: In families where a traditional patriarchal family structure is dominant, the father may make all final decisions about the child, including participation in research. This situation not only prevents the provision of the most fundamental rights of the child, such as the right to participation, but also prevents reaching the child in the face of problems such as neglect and domestic abuse. To overcome this problem, it is necessary to either reach the child without being dependent on the parents in the framework of the principle of the best interests of the child or encourage parents to allow their child to participate in research.

- Parental beliefs: Factors specific to parents come into play and may negatively affect children's participation in research. Namely, in cases of neglect and domestic abuse, parents likely will not want their children to participate in CAN research to protect them or other family members because of collectivism. The findings of studies on reasons for the late disclosure of child victimisation (Koçtürk & Bilginer, 2020) and withdrawal of complaints (Koçtürk & Bilginer, 2019) also support this view. Sharing problems experienced in the family with others is not desired, as reflected in proverbs such as 'The arm is broken, but it remains in the sleeve.' In other words, macrosystem factors such as culture and ideologies also play a role in the microsystem by influencing parents' attitudes, beliefs and values.
- Parental knowledge and myths: Various myths exist among parents about sexual abuse and disclosure (Kızıldağ & Koçtürk, 2021). These sexual abuse myths specific to the victim, abuser and abuse may also prevent their children from participating in CAN research (e.g. 'Preschoolers all make up that they've been sexually abused'; Kızıldağ & Koçtürk, 2021). Parents who are not abusive do not consider it positive to conduct research on these issues because they see talking about sexuality as a taboo and fear the influence on their children. For example, in one study, 70% of parents reported that talking to their children about sexual abuse is against their beliefs and culture (Üstündağ, 2022). Some nonabusive parents in Turkey do not find it positive to conduct research on sexual abuse, because they consider it taboo to talk about sexuality and think that any questions about sexuality do not match and might adversely affect their child's sexual development. To prevent possible reactions from parents and not affect their children, CAN research may not be allowed by authorised institutions, including ethical committees (Uslu & Kapçı, 2014). This situation hinders research on CAN survivors.
- Fearing of conflict with parents: Studies on CAN are not institutionally favoured due to misconceptions and attitudes such as not confronting parents institutionally (e.g. family getting angry with school administrators for reporting suspected abuse to the authorities; Kabul & Bıkmazer, 2022), not dealing with processes such as forensic notification because it requires additional time and effort (Haylı & Durmuş, 2015), the fact that sexuality is taboo, and because some parents use corporal punishment with their children for disciplinary purposes. Experts working with children fear conflict with parents because they feel alone and have security concerns in any conflict situation (Siviş-Çetinkaya, 2015). In this context, mesosystem and macrosystem factors indirectly prevent access to children.
- Difficulty reaching children: Families with low socioeconomic levels in Turkey do not send their children to preschool (Toran & Özgen, 2018). Considering that the first people to be told about neglect and abuse in the family experienced by children are the people close to the children, in the absence of the educator, disclosure of abuse is difficult, unless children interact with a different social environment and develop trust in a person. At this point, the microsystem through which access to children can be provided in Turkey is health institutions. Considering that some children in Turkey are not taken to health

institutions even for compulsory vaccinations (Bozkurt, 2018; Kurçer et al., 2005), it becomes difficult to reach some preschool children in rural areas or in families with low socioeconomic status. On the other hand, although children's councils have been established by official institutions such as the Ministry of Family and Social Services and municipalities to ensure the participation of children in decisions on issues such as municipal activities, these children's councils are not available in every province and district (Erbay, 2013). Similarly, few nongovernmental organisations allow children to take an active role, and they do not have microsystem resources to present their views via the internet or phone. In summary, apart from child follow-up centres where children who are victims of sexual abuse are interviewed and a few associations and child protection units, no other formal or informal services can advocate for children.

Mesosystem

As previously highlighted, the mesosystem involves the relationship between two or more microsystems in which the developing person actively participates. In this context, parental interactions with health institutions or school are the most common mesosystem concepts we encounter. However, factors related to child neglect, such as parents' indifference, unwillingness, lack of time and low level of education, are barriers to parental involvement with health and education institutions (Toran & Özgen, 2018). Considering that the involvement of neglectful parents may already be low, low parental involvement can also reduce children's participation in CAN research. On the other hand, the insufficient number of health personnel, teachers and school psychological counsellors prevents meeting with parents by making home visits. In summary, it is difficult to get legal permission (i.e. informed consent) from parents in cases where parental involvement is low due to the lack of a follow-up system where interviews between experts and family members are mandatory. This situation not only prevents the identification of children who are victims of CAN but also prevents children from participating in CAN research.

Exosystem

Regarding school curricula and media as exosystem variables, child participation is not at the desired level in both areas (Beyazova et al., 2016; Şirin, 2014), and there is no national programme or policy on raising awareness or participation in research on CAN in the school curriculum or media. Similarly, no programmes are conducted across the country for parents. However, the media is a key source of CAN information for families, according to a study by Rheingold et al. (2012), demonstrating that the exosystem can affect how families comprehend CAN. In Turkey, the media does not fulfil the duty of educating society about CAN, and it broadcasts in a way that does not comply with the ethical principles of journalism in terms of language, style and how the news is presented and may lead to the revictimisation of the child (e.g. revealing the identity of the victim, publishing the victim's photo, not believing the victim's statement; Çakmak, 2018). As Bandura (1973) suggested in social learning theory, the child can learn through observation of various channels such as the social environment, media and school curriculum and predict what they may encounter in the society in which they live if they report a CAN event. In other words, the fact that a CAN incident is seen and being presented as something shameful in society may lead to the fear of being revealed as a survivor (Kabul & Bıkmazer, 2022). This situation can be considered an indirect factor affecting children's participation in research.

Macrosystem

Regarding the formation, emergence and intervention processes of CAN, the effects of culture at the individual, familial and country levels are evident. At the individual level, not wanting to be stigmatised or labelled, such as wanting to forget the event by avoiding triggers or reminders, and the fear of revealing one's identity are essential variables that can affect participation in research and the reliability of research results. These variables are not independent of culture. In this context, possible cultural factors that may affect the participation of child victims in research in Turkey can be expressed as follows:

- Beliefs and myths about CAN: Myths about traumatic experiences and victims can be an essential factor influencing the process of reporting and participating in research. For example, the belief that abuse must be concealed to protect the family's honour (Koçtürk & Bilginer, 2020) or that talking about traumatic events can increase pain (Özbağrıaçık-Çağlayan, 2014) are examples of these myths. Other beliefs in the existing culture include trying to forget rather than expressing embarrassing events to preserve honour or dignity. These beliefs can influence the behaviour of victims. In the ecological system approach, cultural beliefs indirectly direct individuals' behaviour (Bronfenbrenner, 1979).
- Sexist culture: Myths that blame the victim are also an extension of sexism and fed by the culture in which the individual lives (e.g. 'If sexual abuse has occurred more than once, the victim has consented'; Koçtürk & Kızıldağ, 2018). Unfortunately, these incorrect cultural teachings in Turkey are sometimes conveyed to the child through a comment by their parents or other individuals in their social circle (microsystem) and sometimes through a news report or words of judgment on television or social media (exosystem). This situation may affect victims' participation in research in Turkey, which is a collectivist culture.
- Stigmatisation of the child: According to the findings of studies on trauma and myths, CAN victims are ashamed of the event they have experienced and hide it to avoid being labelled and excluded (Koçtürk & Bilginer, 2019, 2020; Sayın et al., 2013). In this context, it would be helpful to consider social desirability as an essential factor that may affect the participation of survivors in research (Bergen & Labonté, 2020; DiLillo et al., 2006).

- Fear of exclusion and stigmatisation of the family by society: In the familial context, parents' fears of discrimination or exclusion from society often prevent the disclosure of abuse experiences. This culture is modelled as extremely strong to young children via the verbal and nonverbal behaviours of their parents and social environment such that even if they think that their parents will support them, children often do not report their abusive experiences due to various fears (Koçtürk & Bilginer, 2020). For example, in a study with victims of sexual abuse in Turkey, children's most common causes of delayed reporting were fear of creating domestic problems, upsetting their parents and being identified with the event in their social environment (Koçtürk & Bilginer, 2020). In Turkey, where family values and collectivism are praised, it may be inevitable that the individual needs of victims are ignored, and that they want to avoid reporting for the sake of familial and cultural elements. In other words, there is a fear that experiences of abuse may lead to negative consequences in the family such as exclusion and stigmatisation in society, and dishonouring the family. That would explain why children often do not participate in CAN research.
- Insufficient tracking capacity of the child protection systems: The child protection system in Turkey does not yet have sufficient resources to reach out to and manage all cases considered at risk of CAN in their families, which can be also a critical macrosystemic variable that affects identifying the monitoring of child abuse at societal level.

In summary, from an ecological point of view, many factors that prevent access to children arise from macrosystem variables such as social values, the desire to avoid possible criticism in society and inadequate child protection systems.

Implications for Increasing Children's Participation in Research

As evidenced in this review, many systemic barriers affect children's participation in CAN research in Turkey, that can be identified especially at microsystem and macrosystem levels. When families with children (microsystem) embrace traditional societal values and judgments related to parental authority and power imbalance (macrosystem), it results in a vicious circle that bars children's access to participation in research. For this reason, it is necessary to carry out intervention and prevention studies at various levels according to the ecological system approach to increase the participation of children experiencing CAN in research and enable them to raise their voices. In light of this information, the following implications for politicians and researchers in increasing children's participation in research can be proposed according to the different ecological levels (Fig. 5.1).

As shown in Fig. 5.1, to create adequate conditions for research with children, the following changes are recommended at the individual, microsystem, mesosystem, exosystem and macrosystemic levels.

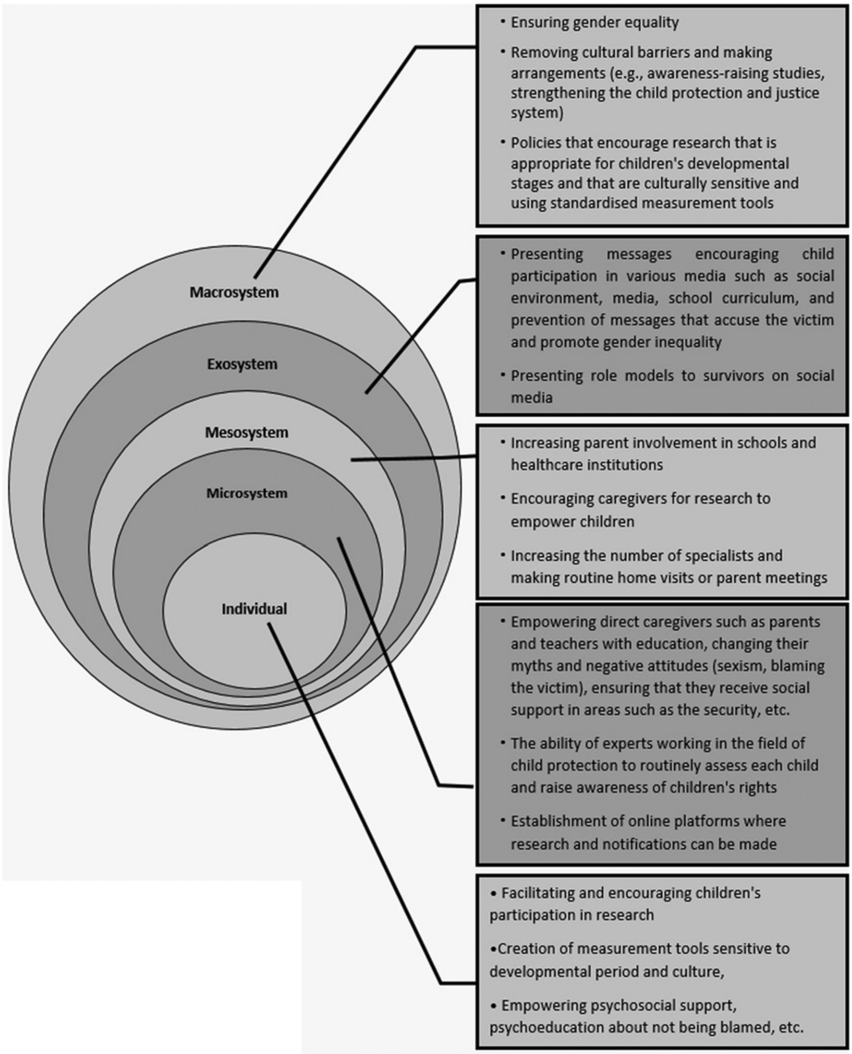

Fig. 5.1. Suggested Implications for Politicians and Researchers to Increase Children's Participation in Research.

Individual Level

Studies can be carried out to understand and influence the values and attitudes of children regarding the reporting of CAN and facilitate and encourage their participation in research. In light of the principle of the child's best interests, caregivers' gatekeeping power should be limited and children's consent should be the primary consideration for CAN research. However, to prevent children from being harmed by research, the content of the research should be evaluated by a scientific ethics board and psychosocial support should be provided to children regarding possible risks after the research. In addition, culturally sensitive measurement tools, which can be used throughout the country, can assess possible CAN exposure among children and identify children who do not want to report, thereby increasing children's participation in research. To increase survivors' self-confidence and eliminate repeat-abuse patterns, studies that psychosocially strengthen survivors should be carried out, and all survivors should be informed about these activities.

Microsystem

It is essential to strengthen family members and experts (such as teachers and health workers) in the microsystem of children, changing their myths and negative attitudes (sexism, blaming the victim) and ensuring that they receive social support in areas such as security following disclosure, to encourage children's participation in research. In addition, parents can be trained on issues such as the importance of talking about CAN and the fact that the taboo regarding this subject can cause much more harm to children. Experts in the field of child protection should routinely evaluate each child and raise awareness of children's rights. Online platforms can be created by the Ministry of Family and Social Services for research and notifications.

Mesosystem

For the mesosystem to be effective, it is essential to increase parental participation in schools and health institutions. In settings such as schools, parents can be trained on myths, the importance of disclosure and gender equality. In expert–parent interviews, parents can also be made aware of their children's participation in research. In addition, parents who do not come to health and education centres can be reached by increasing the number of specialists and making routine home visits.

Exosystem

Messages encouraging child participation should be presented via various channels such as the social environment, media and school curriculum, and these environments should be purged of language that blames the victim and supports gender inequality. Campaigns and studies should explain various social benefits, such as how research with survivors can guide services to be provided to children and contribute to the prevention of CAN. By presenting role models to survivors on social media, survivors can gain the self-confidence to express themselves and be encouraged to participate in research.

Macrosystem

Considering the positive relationship between abuse myths and sexism in Turkey and that gender equality is not at the desired level, one of the most important strategies at the macro level is to reduce patriarchal structures and ensure gender equality. It is essential to remove cultural barriers and make arrangements in various fields to increase the research participation of children who are victims of CAN. First, a social environment should be created in which survivors do not feel shame, blame themselves or feel excluded or stigmatised by their social environment. For this to occur, experts and media should emphasise that the victims have nothing to be ashamed of; the real culprit who should be embarrassed is the abuser and any community that tries to hide the incident and blame the victim. In this context, awareness-raising studies should be carried out to prevent society's negative attitudes towards these individuals. Creating an environment free from social norms and laws that blame the victim may indirectly affect participation in research. Creating policies that ensure gender equality in all macro and micro areas is one step that can be taken in the context of the macrosystem (e.g. strengthening the child protection and justice system). Last, at the macro level, it is necessary to create policies that protect children's best interests and encourage research that uses measures that are culturally sensitive, appropriate for children's developmental periods and standardised.

Conclusions

From an ecological point of view, why children who are victims of CAN are less involved in research takes into account not only the characteristics of the caregiver and child but also the interaction of various environmental and systemic factors that can facilitate or hinder participation of children in research. Interventions and studies on CAN should occur in all domains emphasised by ecological theory that affect the risk of exposure to CAN and the possibility of accessing interventions and support. Finally, given the impact of the macrosystem on other ecological environments (such as family and school), a national policy should be developed to increase the participation of child victims in research and cultural barriers should be studied at each ecological system level.

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Chapter 6

‘Play&Talk: The Magic Cards of Foster Care’: A Research Tool to Interview Children and Young People in Foster Care

Nuria Fuentes-Peláez, Gemma Crous and Judit Rabassa

Abstract

This chapter reflects on the use of interviews as a method of data collection with children and presents an innovative tool to encourage children and youth to express their views and opinions about different areas of their life, especially their experiences in foster care. The innovative tool presented is a gamified interview called ‘Play&Talk: The Magic Cards of Foster Care’. The interview progresses through three levels based on the complexity of the topic to be discussed, and the children or young people decide which topics to discuss and in what order to discuss them. Seventeen children in non-kinship foster care participated for the first time in the Play&Talk interviews in a research context. Based on this experience, this chapter discusses ethical issues relevant to promoting children’s expression and fully realising their right to be heard and express their opinions. The age of the children (6–11 and 12–17 years old) was considered in design and data collection. It conditioned how children received the research information, how they completed informed consent, the use of language, the selection of questions and feedback regarding the results. In addition, the chapter discusses how to involve children and youth in research and their relationship with researchers. This research tool is an example of how to offer children a more participatory role in research interviews and illustrates the importance of age-appropriate designs.

Keywords: Research tool; gamified interview; children’s participation; foster care; play; data collection

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Introduction

The adoption of the United Nations Convention on the Rights of the Child has opened a debate on the participation of children in the protection system, in both practice and research (Kiili & Moilanen, 2019). This debate has affected research with children in out-of-home care since the beginning of the last century and has greatly expanded the number of research studies that directly elicited the views and experiences of children and young people in foster care (Holland, 2009). This increase in research has consequently led to new discussions on how to involve children in research.

Children and young people from the childcare protection system follow a life path affected by traumatic experiences (e.g. abandonment, neglect, maltreatment). Because of these past experiences, it is difficult and delicate to talk about their life in foster care (Falch-Eriksen et al., 2021) due to their inability to trust and confide in adults, alongside the lack of tools and spaces among service providers to explore and evaluate children's experiences in foster care.

Exploring research tools to help children express their voices and opinions about their experiences in the child protection system in a participative, secure and trustful environment is one way of responding to children's and young people's participation rights. However, there is a gap in knowledge and tools that can help children with a foster care background express their feelings.

The game 'Play&Talk: The Magic Cards of Foster Care' (Fuentes-Peláez et al., 2021) that is presented in this chapter attempts to overcome this gap by transforming the classical interview method via play. The aim of the game is to guide an interview and facilitate communication with children and young people in foster care. The tool encourages children and young people to answer questions through play, promoting the creation of a safe space and encouraging communication about their general and specific experiences and emotions in foster care. For example, the tool proposes different topics to talk about such as their foster care environment, friends and classmates, teachers, biological family or even the emotions with which they struggle.

It is essential to address the competencies of researchers to talk to children, promote research with a child participation perspective and create a safe and positive experience. Kiili and Moilanen (2019) pointed to three key ideas: being clearer about the purpose of the research, allowing time to work on trust while preparing for research with children and paying attention to how to involve children in research and maintain safety in the process. Active listening should also be considered in this child participation approach to recognition. The Play&Talk game creates a safe and positive space for children in these varied ways.

The theoretical background of the tool relies on the idea that board games can be for fun and learning at the same time, so they are playful and also educative (Donovan, 2017). Therefore, board games can be a very powerful tool for researchers (Neag, 2019).

Neag (2019) presented a board game designed for research with unaccompanied refugee children. The author presented the game as 'a unique approach to interviewing that proved to be successful in gaining in-depth data. The research tool used (a board game) helped overcome some of the issues highlighted above by addressing the challenges of vulnerability, cultural differences and diverging world views through focusing on the universal language of "play"' (Neag, 2019, p. 255). The aim of Play&Talk is the same as Neag's game: to interview children and get in-depth data through play.

The theoretical background of the tool's content involves some of the application guidelines of the secure base model (Centre for Research on Children and Families, 2022). The secure base model, developed by Schofield and Beek (2014), presents a framework for building positive relationships and promoting security and resilience among children who have been placed out of the home. The secure base has its origins in attachment theory, and the model proposes five dimensions that should be considered to create a safe space: availability, or helping the child trust; sensitivity, or helping the child manage their feelings; acceptance, or building the child's self-esteem; cooperation, or helping the child feel effective; and membership, or helping the child belong (Schofield & Beek, 2014). If we consider these five dimensions from the perspective of research, when we want to promote children's participation, it is very important to build this environment of positive relationships and promote security. The five dimensions helped the creators of Play&Talk draft the first questions of the interview then transform them into a board game. The first draft considered aspects of the daily life of children in foster care, alongside aspects of these five dimensions that foster families might or might not build.

Objectives

This chapter has two objectives: (a) to present the development and outcomes of a tool designed for research with children and young people in foster care and (b) to reflect on the ethical questions that arise when conducting research with children from the child protection system.

The Play&Talk Game

Why?

The game has three objectives: (a) to create a playful and safe environment that makes it possible to delve into emotional issues, respecting participants' decisions about what they want to share; (b) to motivate children and young people to answer questions through play by promoting communication about their general and specific experiences and feelings during foster care and (c) to give children agency by encouraging their participation in choosing the topics that guide the conversation.

How Was the Game Designed?

Once we had the interview guide, we transformed it into a board game in which children take an active role by choosing the topics they want to talk about playfully. A group of adult experts on the topic of child abuse and neglect, with experience in interviewing children from the child protection system, designed the content. A professional graphic designer designed the board game and its cards.

The initial version of Play&Talk was tested and discussed with a 15-year-old girl who was not in foster care but had knowledge of being in foster care.

The pilot test was conducted in four phases. Phase 1 involved an explanation of the pilot experience and interview process. Once the girl agreed to participate, she received a detailed explanation about the board game and the aim of the tool. Phase 2 involved engaging in the Play&Talk game. This process took 1.5 hours. In Phase 3, the researcher sought suggestions and comments related to the content, process and design of the interview tool. Questions referenced: (a) the clarity of the interview questions; (b) the topics addressed, with a focus on adding more topics if needed or changing existing ones; (c) the importance and interest of the content; (d) the design of the tool and (e) the clarity of the instructions. Finally, in Phase 4, the participant suggested other modifications to the vocabulary and language used to make it clearer and more understandable according to the stakeholders' characteristics. For example, she suggested simplifying some vocabulary and making the game less formal, such as the use of the word 'happiness' instead of the word 'satisfaction'.

With the permission of the participant, the pilot experience was audio recorded. Considering the information from the pilot test, the research team discussed all suggestions according to the purpose and theoretical background of the study, then made modifications and additions to the interview tool. Improvements were incorporated in both the questions and the illustrative drawings.

Game Materials

The game consists of a box containing a board, one deck of 17 question cards for players from 6–11 years old, one deck of 19 question cards for players from 12 to 17 years old, three white wild cards and three tokens (see Fig. 6.1). Each card has a topic title and a small drawing on one side and questions on the other side.

The game needs a minimum of two players: a child or young person and an interviewer. No training is needed to use this tool. The instructions and main guidelines are written on the box that contains all the materials.

The two decks of questions are used based on the age of the player: 6–11 or 12–17 years old. Cards differ depending on age. To adapt the game to younger kids who might be less able focus their attention for a long time, the deck for children is shorter, contains two fewer cards than the other deck, every card has fewer questions and questions are simpler regarding vocabulary and content. For example, a card about the player's foster care family has two questions for children aged 6–11: 'Who are your foster family?' And 'Do you like living with your foster family?' In contrast, the same card in the deck for players aged 12–17 has

Fig. 6.1. The Materials From the 'Play&Talk'.

four questions: 'Do you like being with your foster family?' 'Who do you consider part of your foster family?' 'What makes you feel part of your foster family?' and 'Do you think that you are important for your foster family?'

In each deck, cards are organised with three colours. Each colour represents a level. The first level, 'social and daily life', is yellow. The second level, 'emotions, living together, and communication', is green. The third level, 'foster care relationships', is blue. Each level corresponds in different depths of the player's life. See Table 6.1 for more details on the topics addressed in each deck of cards.

All materials of Play&Talk were designed only in the Catalan language, the official language in Catalonia (the region of Spain where the game was created). The questions noted before have been translated into English for this chapter.

Game Instructions

Play&Talk should be played in a space where the child or young person is likely to feel comfortable, to create a safe, trusting and stimulating space. Thus, Play&-Talk can be played in the child's bedroom, living room, a park nearby or even the facilities of an institution that organises foster care and where social workers and other professionals work. Apart from the setting, it is important to adapt the time of the meeting to the children's and their family's convenience. The game should be played only with the child or young person, without their foster care family.

Table 6.1. Topics That Contain Each Deck of the Play&Talk Cards.

	Ages 6–11 and 12–17	**Ages 12–17 Only**
Level 1: Routine and everyday life	Day-to-day activities Rules School Social and school life Homework Leisure time activities	Teachers from school
Level 2: Emotions	Trust My emotions Expression of my emotions Self-esteem Communication Living together	Dealing with my emotions
Level 3: Foster care life	Foster care family Biological family Other family members Professionals from foster care team Me and foster care life	

This ensures that the participant gives sincere answers and is not biased by the presence of their family.

The game starts with the researcher (who assumes the role of a player while guiding the board game and interview) placing the board game on a table or the floor (depending on where the participant feels more comfortable sitting). The researcher chooses a deck of cards according to the age of the player, sorts the cards so that there are three piles according to the three colours (i.e. levels) and places them on the three rectangles marked on the board. Each rectangle is the same colour as the corresponding level.

The game starts with the stack that corresponds to the first level. The researcher distributes the cards on the table with the drawings and titles of the topics facing up and asks the player to choose one. The researcher turns it over, and then the researcher asks the questions on the back of the card by reading them out loud or the player does this if they prefer to read the questions instead of listening to them. Once the questions from one card have been answered, the researcher places the card back on the board in its corresponding rectangle. When all or most of the cards from the first level have been answered and the rectangle has been filled in, the child or young person can take one of the tokens and put in the corresponding box on the board. The token has no implications. The only meaning is to signal to the child or young person that they finished this level. Not all the cards have to be played – at the beginning, it is important to make sure that the player understands that if they do not want to play a card, it is OK because no cards are compulsory. When the child puts the token in its place, it indicates that they finished this level, even if not all cards have been used.

The game continues with the second and third levels in the deck of cards, repeating the same process. The player can go through the three levels, using or playing as many cards as they want, or stop at any time.

In addition, three blank cards can be used in each level when the child or young person wants to talk about another topic that does not appear in the cards and is related to the current level. These cards are available on the table or floor, ready to be used if the child wants to talk about something else. For example, if a child wants to talk about their siblings and no questions have been asked about them, they can use a blank card and start talking about their siblings, then add the card to the corresponding level.

When a card has a picture of a paintbrush on the bottom left corner, it means that the player can choose to answer the questions with a drawing and explain it to the researcher or answer the questions verbally. Not all cards have this symbol; only those for which the research team felt a drawing could help the child express their thoughts. For example, the card about their foster family has a paintbrush because some children might find it easier to draw their family, then talk about their family members.

This game can be played many times with the same participant, because the answers may be different each time. A minimum of one week between games is recommended. The researcher can use the Play&Talk game and write down answers or record the conversation. However, the second option is encouraged, allowing the researcher to be more focused on the game and not writing down responses.

Researcher Role: From Interviewer to Gamer

Play&Talk proposes a different role for the researcher in the interview process. The role of the research interviewer shifts from what is expected in a traditional interview, where the interviewer seeks mainly to obtain answers to questions and elicit new questions. In this case, the role of the researcher is more like a gamer or conductor who facilitates the development of a conversation through play, rather than an interviewer who sticks to a predetermined script. There is no order for how the cards should be answered, nor an obligation to answer them all. So the researcher has to follow the lead of the player. This means that the researcher must have an open mind and let the conversation and game flow. When a child is not answering certain questions, that is an informative result. Different hypotheses about why players might not address certain questions or topics can arise: The topic might not be relevant for children, the topic might be difficult or taboo or maybe the topic was not properly understood. As in any participatory research project, the researchers have to be ready for unexpected results, and when the research is guided by the child, we should respect their decisions.

At the beginning of the game, it is important that the researcher provides an introduction, recalls the information sent with the invitation to participate in the research and offers an opportunity to address doubts (for information and recommendations on how to recruit participants, see the following section). The researcher should explain the rules of the game and its development in a simple but clear way, emphasising how to participate or withdraw. In this context, the researcher is expected to both encourage the child's expression through the choice of cards and use active listening. The researcher must stimulate and encourage the child to choose the topics that motivate them, initiate conversations about these topics and respect their silences during conversation. However, it is not enough to ask the questions that appear on the cards. To promote the authentic 'child voice' (Lewis, 2010), it is important to know how to listen by making the play space safe so that the children do not keep silent about their thoughts or opinions. Nevertheless, offering them the opportunity to express themselves is not enough; as Lundy (2007) said, 'voice is not enough'. Active listening is necessary. In other words, the researcher must let the child know that they are being listened to and that the researcher is interested in what they have to say.

Who Played the Game for the First Time?

Play&Talk was tested for the first time in 2020 through the participation of 17 children placed in nonkinship foster care. Regarding the demographic characteristics of the participants, 64.71% (n = 11) were between 6 and 11 years old and 35.29% (n = 6) were between 12 and 17 years old; 52.94% (n = 9) were girls and 47.06% (n = 8) were boys. In addition, 65% of the children had contact with their biological family and 53% were in a long-term foster care placement (see Table 6.2).

The recruitment of participants was done through the institution responsible for foster care in Catalonia, Spain. The institution and its professionals who are in contact with foster care families and follow their progress reached out to potential participants. This process involved sending an infographic and video via email to the foster care families of children and young people. The information relayed the objective of the research, its importance, the methodology involved and why their participation is being sought. This information was adapted to be understandable to children. The video includes drawings and schematic information.

When foster care children and their families agreed to participate, interviews using Play&Talk were scheduled for a day and time that was convenient for them, and participants also selected the setting.

The game took between 30 and 80 minutes. The duration depended on the age of the child: Younger participants couldn't stay focused for a long time, so the game was shorter. All participants collaborated on the interview, answering as many questions as they wanted, and they were not forced to talk more about something or have their explanations cut short by the researcher. At the end of the

Table 6.2. Demographic Characteristics of Children and Youngsters in Nonkinship Foster Care Participating in Research.

Gender	Age	Contact With Biological Family	Type of Foster Care	Children Participants
Boys (*n* = 8)	6–11 (*n* = 6)	Yes (*n* = 3)	Short term (*n* = 2)	1
				1
			Long term (*n* = 1)	1
		No (*n* = 3)	Short term (*n* = 1)	1
			Long term (*n* = 2)	1
				1
	12–17 (*n* = 2)	Yes (*n* = 1)	Long term (*n* = 2)	1
		No (*n* = 1)		1
Girls (*n* = 9)	6–11 (*n* = 5)	Yes (*n* = 4)	Short term (*n* = 2)	1
				1
			Long term (*n* = 2)	1
				1
		No (*n* = 1)	Short term (*n* = 1)	1
	12–17 (*n* = 4)	Yes (*n* = 3)	Short term (*n* = 2)	1
				1
			Long term (*n* = 1)	1
		No (*n* = 1)	Long term (*n* = 1)	1

interview, participants received a certificate to reinforce the meaning of their participation.

The results of the interviews conducted through the Play&Talk tool illustrate its research utility. Children and young people, through Play&Talk, explained very personal things and deep feelings. For example, on the card about their foster family, one question asks about feeling that they belong to their family. A 14-year-old boy said that his foster parents made him feel like part of the family. The interviewer asked him, 'What things do they do or say to make you feel that way?' He responded, 'They ask me to do things with them. They ask me how I am doing. My [biological] mother never did this before'. It seems like a simple answer, but without a safe space and trusting environment, he might not have shared these feelings.

At the end of the game, the researcher asked the participant if they liked the game. All participants said that they liked it; for example, a 16-year-old girl commented: 'Yes, I liked it. It has been entertaining'.

All interviews were audio recorded, with the prior permission of the participants, to be transcribed and analysed later. The transcriptions were sent to the participants who so wished (not to their caregivers nor professionals, respecting the principle of privacy). This action was meant to reinforce the meaning of the children's and young people's participation.

A few months after the interviews using Play&Talk, some results were presented in an online session open to the children, with whom their meaning was discussed. Results were presented with a very short and visual PowerPoint presentation. The slides contained mainly illustrations, along with some of the participants' quotes. Not all 17 participants could attend the presentation. They offered some comments about the results regarding the areas of their life addressed through the cards. For example, an 8-year-old girl said, 'We should stop being so much worried about the family that you were born with, because we are good with the family that we have now'. They did not comment on the game because it was not the aim of the presentation. However, the presentation was very useful to understand some comments that they made during Play&Talk that researchers did not understand at the time or later when analysing data.

Ethical Questions

Research with vulnerable groups raises ethical challenges (Von Benzon & van Blerk, 2017) that interconnect methodology and ethics to such an extent that both should be considered together (Kiili & Moilanen, 2019). From this premise, we asked ourselves: What ethical challenges are involved in exploring the experiences of children in foster care through research?

Understanding these challenges goes beyond methodology and requires contextualisation in the research process. We approached these ethical challenges from five premises. The first has to do with the meaning of the research for the participants, especially when dealing with children and young people in vulnerable situations. The fact that the participants found meaning through their participation is a basic axis of the ethical bases for the experience to be satisfactory. In line with this, different actions can be taken to reinforce the meaning of their participation: (a) approach the participants in advance and send them appropriate information in an adequate format before the interview; (b) return the transcripts of the interviews to the participants for review and (c) provide a certificate in recognition of their participation.

Closely related to these issues is the acceptance of the children and young people to participate in the research. The personal relationship that the social worker has with them is a facilitator to participate in child protection services (Van Bijleveld et al., 2015). Based on this premise, their professional or foster caregiver provided the recruitment information to the children and young people. With this information, the children or young people gave their assent to participate in the research, along with consent from foster caregivers and the public institution responsible for guardianship.

The third principle has to do with the recognition of the child or young person as an active subject in the interview to minimise the researcher's dominance of the interaction (Lewis, 2010). This premise requires, on one hand, the flexibility of the researcher to adapt to the time and place where the game occurs. That is, the meetings were organised considering the time and place preferred by children and young people. On the other hand, the development of the game emphasised the importance of letting the child choose the topics and order, making it clear that there is no obligation to answer the questions and allowing them to decide when to end the interview.

Fourth, it has to do with creating a safe and trusting space that makes the encounter a positive and empowering experience. The age-appropriate design favours the creation of a trusting and safe space to talk with children about their foster care experiences. In this dimension, the preservation of confidentiality and anonymity also contributes to sharing experiences and through active listening, recognising them.

Finally, another sensitive issue in terms of ethics in research with children is the interpretation of their voices and silences (Lewis, 2010). The action of sending the transcripts to the participants and presenting and discussing the results with them after the analysis can help the researchers understand the results and correctly interpret the children's voices.

Implications and Conclusions

Many of the most important experiences in life occur through play. Play is a right of children and an engine of great learning by allowing the exploration of new paths and facilitating interaction in a particular setting. In addition, playing with children helps us better understand their world, logic and perceptions, so it seems suitable to include it as a methodology in research with participatory approaches. Therefore, continuing to explore the possibilities of bringing the concept of play into research holds great promise (Neag, 2019).

This process involves not only collecting voices or opinions but also interpreting and disseminating these voices (Lewis, 2010). This leads us to the need to consider how to incorporate children and young people in the data analysis. Informative experiences such as that of Liebenberg et al. (2020) illuminate this process. This is the next step of this research project. In a prior study, we included participants in the discussion of the results. The participants contributed with their opinions through a session in which the results were presented. However, it would be interesting to include the participants in the process of data analysis, including choosing what and how data should be analysed.

As previously said, when using a game as a research tool, the researcher needs to take a different role. To develop this role, the researcher must engage skills that favour the creation of a safe, trusting and stimulating space so that the children and young people are encouraged to start the conversation and play. This is not specific to children in foster care but holds true for all children. The researcher should interact with children with an attitude of being personal and representing an individual and not only a researcher (Eriksson & Näsma, 2012). However, it needs to be clear that the role of researchers is very different than the roles of therapists, advocates or social workers (as pointed out by Schelbe et al., 2015), who also might have contact with these children in foster care. The researcher is there to be empathic and listen actively while making sure that the participant knows the aim of the interview and the boundaries of the conversation. Further research and discussion are needed regarding how to achieve a positive and trusting relationship between children who have been exposed to violence and researchers, and under what conditions.

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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

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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

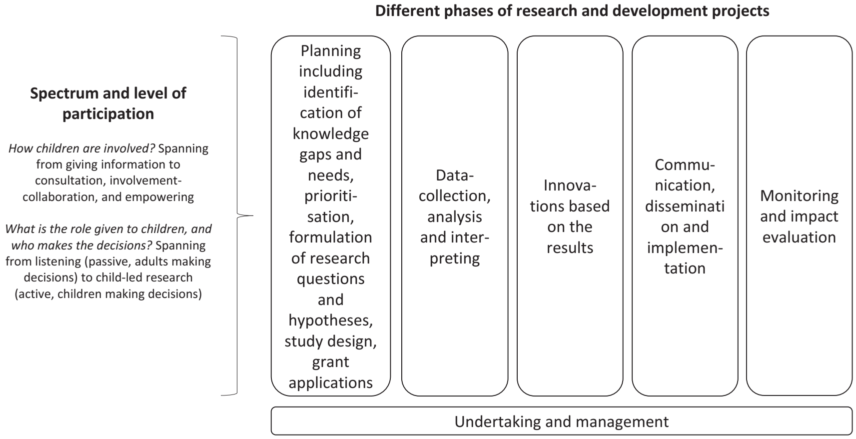

Fig. 7.1. Level and Extent of Child Participation. Children can assume different roles in research projects depending on their needs and possibilities.

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

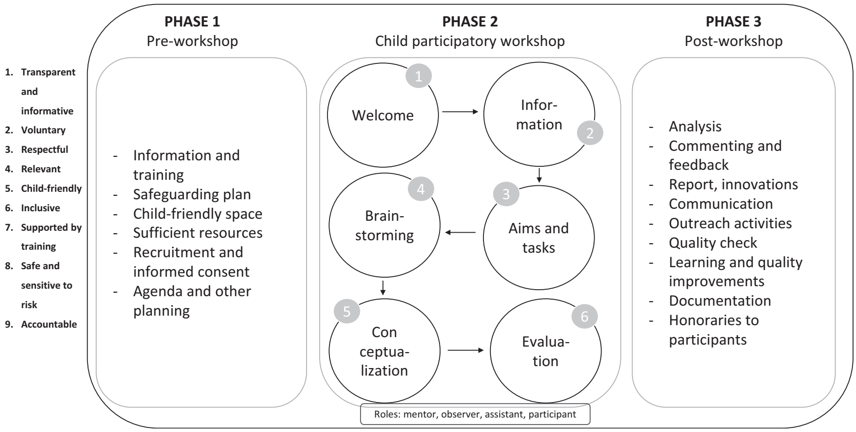

Fig. 7.2. Summary of the Barnafrid Model for Child Participation in Research and Development Activities.

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

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[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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Chapter 8

Digital Technology-Based Research With Young People in the Context of Hungarian Child Protection

Andrea Rácz and Dorottya Sik

Abstract

This chapter discusses how to involve children and young people in decisions and encourage them to express their needs and participate in the decision-making process to develop a quality intervention. By describing the different aspects of projects involving a participatory approach, it shows how giving voice to children and young people unlocked new perspectives regarding the Hungarian child protection system. Participation of children in research is limited in Hungary, partly due to the challenging legislation and authorisation process. This chapter shows how research to develop child-friendly digital tools can contribute to collecting children's views on their needs related to child protection support, and how the process of listening to children can improve parenting and caregiving responses to the needs of younger and older children living with their families or in the child protection system. The chapter analyses the effect of digital applications on children's and young people's capacity to advance towards autonomy, including applications and a video campaign with short video clips created by young people. These projects gave an opportunity for children and youth in the public care system to describe their lives and wishes for the future. The analysis found: (a) for a functional child protection system and to promote development for children and young people, children's voices need to be amplified; (b) by expressing their voices, children become more autonomous; (c) children's voices contribute to decreasing social prejudices against children and young people in public care; and (d) listening to children and youth

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who age out of care can help professionals working in the child protection system better understand their beneficiaries.

Keywords: Hungary; mobile app; digital tools for youth; participatory research; good practices; voice of youth

Introduction

In this chapter, the experience of developing two apps and a video competition is presented as good practice in the Hungarian child protection system to show why it is important to inform and involve children and young people in decisions about their lives and how to encourage them to express their needs in a more targeted way. The opinion of children and young adults can be channelled into the development of high-quality child protection services, and their participation can help professionals better understand their situation and wishes and thus, work together more effectively.

The two online-based tools and video campaign were introduced to create social awareness in Hungarian society of the challenges faced by children and young people in the child welfare and protection system. This proved to be a good example of how although the involvement of vulnerable target groups in research and service development is very limited in Hungary, these programmes were important experiences for child protection professionals and a learning process regarding participatory research methods. The outcome of this participatory research indicates best practices for professionals in the child protection system.

Situation of Children in Hungary

In Hungary, the 1997 Child Protection Act defines the functional, theoretical and practical framework of the Hungarian child protection system. It also defines the fundamental rights and duties of children and their parents; the child protection system, including the benefits and measures taken by the authorities; the child welfare and child protection tasks of the state and local authorities, churches and nongovernmental organisations; and the organisational and main rules of the guardianship administration. The aim of child protection system is to prevent the various social problems that children and their parents face in their daily lives and once they have arisen, to alleviate and eliminate these situations of vulnerability. Nonetheless, systemic barriers exist to meeting this goal in Hungary, including an insufficient professional workforce and high turnover that have led the system to be primarily responsive to acute situations (i.e. ‘firefighting’ work culture), overoccupied with the continually increasing problem of child poverty, and lacking a clear legal definition of child abuse and neglect. A preventive approach, prevention as a way of thinking, and the incorporation of best practices and methods based on this approach are essential, but at present, this cannot be achieved in Hungarian practice (Rácz & Sik, 2020; Révész, 2007; Sik, 2020).

Since the regime change in 1989, the increasing poverty of children has been a problem in Hungary. The proportion of children at risk of poverty or social exclusion in Hungary is 23.8% in 2018, according to a 2018 study (European Court of Auditors, 2020). Child poverty varies widely by region. Children living in small, disadvantaged, segregated settlements have much lower chances of mobility and a higher risk of social exclusion (Rácz & Sik, 2020).

Regarding prevention and effective responses to problems that have already developed or are longstanding, various child protection programmes have a very important role to play, including seeking new ways and innovative methods to reach parents and children. Since 2017, the Rubeus Association has been implementing innovative programmes based on a broad partnership with members of state and municipal and civil representatives of the care system, which aim to provide social professionals working in family and child welfare services and child protection system with effective tools to improve their work, address family problems and contribute to a more conflict-free parent–child relationship by developing parenting skills.

Children's Participation in Evaluation and Development of Child Protection Services

According to the principles recommended by the Council of Europe (2011), 'social services should ensure that the child is heard and taken seriously' (p. 7). Participation of children and their families, including hearing their voices, is not common in the Hungarian child protection system. In the last 30 years, different child protection programmes have been implemented in the country with more or less success, but involvement of children and their families in the creation, development, or evaluation of child protection services still happens only on rare occasions. As recommended by the Council of Europe (2016a, 2016b, 2022) and experts in child participation (Kennan et al., 2016; Larkins et al., 2014), a framework is needed to systematically collect children's views on the welfare and care services directed towards them. As for adult beneficiaries of services, involving children would inform the planning, monitoring and improvement process.

The involvement of people younger than 18 in research is generally challenging and requires child-friendly methods (Punch, 2002). Success in creating spaces for participation (Council of Europe, 2016a) in child welfare services depends even more on methods used for consultation or collaboration with adults or initiation of research to evaluate and improve social services.

In the Hungarian child protection system, methods to involve children in evaluative or action research are rarely used. One reason is the challenges of working with children and young people in care and the scarcity of good practices adapted to their age-related needs that would facilitate the expression of their opinions. Another reason is related to present legislation – to involve children in research, a complicated authorisation procedure is required (Care Inspectorate, 2012; Cossar et al., 2013). Thus, the involvement of children in research on issues that concern them is negligible in Hungary. 'While many researchers argue for the inclusion of children in research because of the neglected perspective of children and their rights to participation, the primacy of children's protection can have a significant impact on their actual participation' (Kutrovátz, 2016, p. 89).

Aiming to respond to the recommendations of the Council of Europe, this study explored how using digital tools to give voice to children is a way to make this process interesting and worthy for children and young adults (Bidargaddi et al., 2017; Dute et al., 2016; Grist et al., 2017; Rácz et al., 2022).

Two apps, YounGO and Asszerteen, were developed based on the notion that for adolescents with history of child maltreatment and abandonment or with some kind of child protection problem, starting an independent life upon becoming young adults is a major challenge, especially when there is none or only a fragmented safety net around them. Professionals working with children and young people, helping them in their daily lives and development, often encounter challenging situations linked to crises in their lives (death, illness) or arising from difficulties in the environment (e.g. neglect, family conflicts, abuse). The background to the two applications and video competition involves the Rubeus Association. The Asszerteen app is one development of complex child protection programmes that have been running since 2017.[1] The target groups of these programmes include children and their parents affected by addictions and mental disorders, family abuse, and conflicts. The programmes focus on strengthening the position of children in the family and more broadly, breaking down social stereotypes about children with child protection problems and their parents. In the case of a child who has been removed from the family, the aim is to help then maintain contact and support their effective reintegration.[2]

The YounGo app is an earlier development of the Rubeus Association, but its promotion and conscious use have been integrated into the association's programmes since 2017. YounGo was the basis of the Who Am I? video campaign.

The two apps were created to support children as they face difficult life situations, with the aim of helping them develop the skills they need to live independently in the future (FIFTI, 2016; Rácz, 2017; Rácz & Bulyáki, 2021). In describing the process of developing the apps, this chapter outlines the role of participatory research with children and how their views were incorporated into the apps' finalisation.

It is important to note that on the international level, many applications exist. The goal of these apps is to help disadvantaged children and young adults to become more independent, increase their social integration and develop their

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[1] The results and outcomes of these complex programmes are presented by Rácz and Homoki (2021); see http://rubeus.hu.

[2] The results of research regarding the effectiveness of the Rubeus Association programmes (with participants including parents, children and professionals via quantitative and qualitative methods) show that involving the participants improved parental skills, strengthened the relationship between parents and children, and decreased the social disadvantages of children. Professionals gained self-confidence and awareness, helping them build partnerships with their clients (Rácz & Homoki, 2021).

social skills. The apps reflect the main topics important for growing up successfully, such as housing, education, health, family and relationships.

The results show that young people find these apps useful and prefer them as a way of communicating. The apps help them navigate challenges in their life and provide them up-to-date information. The apps have information about available helplines, so users can access them easily. The organised information also helps professionals connect with young people (Bidargaddi et al., 2017; Dute et al., 2016; Grist et al., 2017; Rácz et al., 2022).

YounGo

The development of the YounGo – Help, I'm Growing Up! phone app involved child protection professionals, researchers and young people placed in the child protection system. The YounGo app is based on thematic groups, which are called clubs,[3] and a comic book that describes the specialised care sector, raising awareness of the need for an effective and innovative form of support to help children become autonomous adults. The primary target group of the project is children and young people aged 12–30 growing up without a family in the child protection system. The secondary target group of the project are professionals (social workers, educators, foster parents and guardians) working with children.

The development of the app involved three key studies involving children and young people. Their participation in these studies helped improve the quality of the app. With the help of children, the topics, language and design of the app were more likely to fit the concerned target groups.

Study 1: Focus Groups With Children, Young Adults and Professionals

Participants and Methods

The development process of YounGo was based on focus group interviews regarding the thematic clubs. The goal during the development of YounGo was to determine what kind of support they would need to become adults, what topics they would be interested in and who they would consider credible in terms of providing the information they want. To get information about all these needed supports, four focus groups were conducted with the aim to hear the voices of the children, young adults and professionals who would use the app. The sample for

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[3] The thematic groups or clubs were led by child protection professionals. Each group consisted of five sessions. The theme was, according to the research, helping adolescents become adults. The sessions were interactive, such that every topic was elaborated through group games based on the experiences of the participants. For example, in the topic of school and work career and job search, the participants discussed their school and work career plans, practiced curriculum vitae writing and focused on available mentor programmes and successful ways of job searching. To support the participation of the adolescents, group activities were important and necessary: In the group sessions, the participants had the opportunity to share their opinions, point of view and needs, and give feedback about the sessions (see the detailed script of the sessions in FIFTI, 2016).

the focus groups included (a) children aged 14–18 and living in children's homes, (b) children aged 14–18 and living in foster care, (c) young adults aged 19–25 and living in the aftercare system, and (d) professionals (social workers, educators, foster parents and guardians). Twenty children and youth participated, with six to eight members per group. The focus groups were overseen by researchers, and the topics discussed were school experiences, experiences in the child protection system, leisure time, friends and social connections, and challenges of growing up (housing, job search, earning money). Consent from the guardians of minor participants was received prior to the focus groups. The focus groups were conducted according to the guidelines and recorded and transcribed verbatim. The interviews were anonymised for analysis.

The focus groups took place in a new environment: a club room designed for kids where they were offered snacks and drinks and had time to get to know other children from different foster homes. Therefore, the setting of the focus groups developed an atmosphere where young people seemed comfortable and able to express their views in an informal way, sharing their experiences with people from different care settings.

Results

Partly because of their different care placements and partly because of their child protection status, the topics these participants considered important in terms of independent living, the depth of information they had on these topics and their sources of information were minimal. However, several important themes concerning children's needs were identified through these focus groups.

A main difference between growing up in residential homes or with foster parents regarding preparing for independent living was the importance of time management and recreation. Children in public care perceived sports and hobbies as playing a more important role in their lives than those in residential care. In the process of developing the app, these outcomes were considered, resulting in mental health and recreation as a focus of the app. Participants were unanimous in their opinion that they had found emotional stability in their care placement and integrated into the family, even if they lacked knowledge and concrete plans for starting their lives in many areas. 'It's very good for me that I can always count on them, no matter what, no matter what the problem. They are always there for me. So, we are very close, we love them very much' (Participant aged 14–18 and living in residential care).

When asked how they had experienced coming of age and whether they received help in preparing for the new challenges of adulthood, many participants answered in the negative. In relation to the transition to aftercare, young adults reported that they had not received the necessary preparation and that they still felt like children. Many had concrete plans for their future, but they still had much uncertainty about implementation and detailed steps needed to achieve the plan. When asked about practical tasks of everyday life, such as administration and money management, young adults reported that they often find it difficult to manage simple situations without help. Their opinions were a great help in structuring the content of the programme and app. 'I didn't even know [about] a card, an OTP debit card, because I was afraid to go in because, what can I say? I might not understand what he's talking about, and I'll be sitting there like an idiot' (Participant aged 19–25 and living in aftercare system).

Respondents also welcomed help with psychological conflicts and managing social relationships. Many reported crisis situations in which they greatly needed adequate support, such as struggles with depression, dealing with a breakup, experiences of abuse, and alcohol and substance abuse. When developing the apps, we considered that the young people who were interviewed found it difficult to talk about sensitive issues and had a strong need to reach helplines when in crisis.

Study 2

Following the results of the first study, five clubs focussed on preparing for independent living were created in two locations in Hungary based on the wishes and interests of these participants. The experiences of these clubs were summarised in a handbook (FIFTI, 2016). This was followed by a request for an information and communication technology-based form of assistance that would always be accessible and updated in the language and on the topics of interest to young people. The resulting YounGo app cover topics related to growing up, such as further education, housing, sexuality, living without love, relationships, finding a job and having children. Young people played an important role in both the identification of the themes and the app's design, given their views have been sought at every stage of the project.

The app can be downloaded to smartphones for free, and there is an accessible website, too. The app contains information about several categories (such as children's rights, school, job search, health, housing and helplines). Each category is divided into further subcategories. Each category contains links to additional websites, short films, downloadable documentaries and short text descriptions of each topic. For example, the topic about choosing a career has four subthemes: Which school should I choose?; What are my talents?; career choice guide – questionnaires and service providers; and mentoring programmes and scholarships.

Study 3: Testing the App

Before the app was launched, 50 children and young adults in child protection services tested it and gave their input; most of them participated in focus groups, too. The testing took place in groups in different care settings, where everyone tried the app or its equivalent website at the same time. Participants provided feedback on both content and design in discussions. Test results indicated that the app was very well received by children and young adults, easy to use, logical and comfortable. In their opinion, the wording of the content available in the app was to their taste, and the content was rich in news and up-to-date information.

Based on their opinion, the app was finalised in terms of what topics would be important to support independent living, adding topics such as cooking economical meals or accessing helplines. They also asked for information on low-cost housing solutions and services available to improve their self-awareness.

The widespread use of the app has to occur, but the feedback shows clearly that this tool can help not only children and young people but also professionals working with them on a daily basis (FIFTI, 2016; Rácz, 2017; Rácz & Bulyáki, 2021; Rácz et al., 2021). It is important to note that on an international level, many applications exist. The goal of these apps is to help disadvantaged children and young adults become more independent, increase their social integration and develop their social skills. The apps reflect the main topics of importance to growing up successfully such as housing, education, health, family and relationships. According to the results, the target group can use the app and the organised information available through the apps to understand the world around them, access helplines and contact professionals (Bidargaddi et al., 2017; Dute et al., 2016; Grist et al., 2017; Rácz et al., 2022).

Dissemination

To promote the app and introduce good practices into child protection, a large-scale Facebook campaign was run in 2018 and a competition was organised among young people to take photos reflecting aspects of their lives and challenges based on the themes of the app. In the Who Am I? campaign, we asked young people to use the app to present their lives and the challenges of growing up through its themes.

Asszerteen

The Awakenings Foundation,[4] a partner of the Rubeus Association, developed Asszerteen in 2020 and 2021. This app had an organisational predecessor in 2017, Asszertívia, an app that teaches assertive communication and helps people with mental health problems and psychosocial disabilities to cope with difficult everyday life situations and learn assertive communication patterns. This app was further developed with children and young people from child welfare and child protection backgrounds.

Asszerteen's stated aim is to develop teenagers' assertive communication and stress management skills in an easy-to-learn format. It features three domains – positive prompts, negative feelings and positive feelings – which consist of short modules of 5–15 minutes. The free course takes place in a virtual city (Asszertívia), and the user is asked to choose effective expressions and reactions from a set of options for characters (from different generations) in everyday life situations The app first briefly presents the aim of assertive communication to young people and then builds on hypothetical situations where they learn to notice and

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[4] https://ebredesek.hu/e

understand assertive communication. It is important to learn how to give feedback in certain pleasant or unpleasant situations. There are also short explanations for each situation so that they learn the correct, inoffensive way to express their feelings. In each task, the users choose from emotion emojis to learn to recognise and express their feelings. The end goal of Asszerteen is to help them use assertive communication in everyday situations with their friends and adults – e.g. dare to ask for favours or help or say no to requests that are inconvenient for them.

The course is accompanied by audio materials. The communication skills exercises were tested and discussed by young people.

As was the case with YounGo, children participated in the development of Asszerteen via research and later tested the app.

Stage 1: Interviews With Children and Professionals

Participants and Methods

As a first step in the development of the app, a needs assessment was carried out through group discussions with six professionals working with young people (social workers, school social workers and psychologists) and teenagers (eight girls, four boys) involved in child protection. The teenage participants were 14–17 years old. One needs assessment interview was held with professionals and three with the target group. The three group interviews with young people explored their knowledge, interest and sensitivity regarding communication and its difficulties with siblings, parents and professionals. The setting of the focus groups was similar to the YounGo study: a neutral and safe place with snacks and drinks and a calm and welcoming atmosphere.

Results

The interviews explored life situations that are sources of difficulties in the lives of teenagers, including their family life, relationships with their peers and in the adult world, and society at large. The interviews revealed that the main concerns in relation to peers are bullying, name calling, teasing, and exclusion and how they can prevent and deal with these issues effectively. Examples were given of the hurtful impact of remarks about appearance, body type or differences in financial means. In relation to the family, the focus was on conflict and the difficulty of divorce, with participants reporting feeling helpless and their parents being irritated. Similarly, the need for help with schooling was identified as an imbalanced communication situation, in which the parents don't understand them, and a source of conflict in the parent–child relationship because of academic performance.

Stage 2: Testing and Finalising the App

The young people were involved in the preparation of the content and design of the app and individually commented on the app multiple times during its testing phase.

For each module, they could indicate in writing whether they would change it and if so, what they would change. Some participants also made textual suggestions on how a communication situation and response options should be presented in the app. For example, participants indicated the phrase ‘My old man just doesn’t understand me’ should be modified because the term ‘my old man’ is not used to refer to fathers. Based on the feedback received, situations and tasks in the app were finalised. The development process in every phase involved the participants, and their reception was very positive in every round (Rácz & Bulyáki, 2021).

The two apps, representing good practice from a child-protection perspective, are unique ICT-based tools that aim to develop skills, build self-confidence and prepare children for independent living in the long term. Table 8.1 presents the outcomes and experiences of the apps’ development. They address young people in a modern way, present important topics and life situations, and offer solutions for youth when they feel stuck, whether in a situation involving adults or with their peers, by offering help and support. The latter is done partly through skills development and partly by describing specific helplines and forms of support. A further strength of both apps is that they also address professionals working with young people in an indirect way. They also provide young people and professionals with relevant information in one place. At each stage of development – design, implementation, testing and finalisation – the voice of young people was very much included, and the two development teams sought to ensure that professionals working with the target group were also involved. The aim of these good practices is to raise social awareness of child protection and the acceptance of those already in child protection specialist care. In 2021, the Rubeus Association launched the Who Am I? campaign to make child protection more visible to society.

Who Am I? Campaign

The Who Am I? campaign was based on a video call for entries, wherein children and young people in child protection or any child protection services could submit a short film about their daily life, interests and plans. We asked for videos of up to 2 minutes in which children and young people could talk about themselves: what they like to do currently and what they would like to do in the future and how they support others (which makes them feel better, even for a minute). Two age categories were announced: 12–14 and 15–18. In total, 37 high-quality entries were received, judged by a professional jury, and ranked via a public vote through a Facebook campaign to increase visibility. The campaign was a success and is currently being considered further. Thousands of people voted for the best entries on Facebook. At the seminar where results were presented, participants said they were keen to work on their short films to give an authentic picture of their lives in the child protection system. The Rubeus Association plans to organise more campaigns like this to help children in the public care system raise their voices and show their lives to the rest of society.

Table 8.1. Experiences in Developing Apps to Involve Children.

Apps	Preliminary Research, Consultation Involving Children	Assessment, Testing and Launching the App, Participatory Research	Possible Further Development of the App
YounGo	Missing skills Important topics School, job seeking, deviancies, relations, leaving the child protection system	No redundant topic appears in the list Every main topic is included in the main list Minor amendments needed to finalise certain topics Claims have been formulated for new subtopics	Can be adapted to different child protection, prevention goals The app has to be updated regularly to keep up with new contents and knowledge opinions and interests of users (teens, young adults) are constantly needed to update the content of the apps
Asszerteen	Concerned teens and young adults often face disturbing, harmful and threatening situations. They often are left alone with harsh, difficult emotions after these situations in all parts of their life: peer groups, family and society. Their skills and knowledge about reacting in these situations are fragmented; they need practical advice.	Participating teens and young adults suggested changes, mostly regarding wording. As a result, the app uses the language of teenagers, which improved its approval. Clarity and understandability are important. Simple, clear messages and simple, short and catchy answers are needed.	Education of the children can be done only with the assertive participation of adults. Acceptance is necessary at all levels. Introducing school social work is a chance for children and professionals to connect. The use of this app can help children, parents and professionals better understand each other and value the opinions of children and young adults.

Source: Original work.

Discussion

The examples of good participatory practices presented in this chapter show that for the self-regulation of a child protection system, the voice of children and young people need to be amplified to improve the quality of the system. Expressing their views and voicing their opinions helped children and young people become more independent and develop skills such as self-advocacy, decision-making, relationship-building and assertiveness. Encouraging young people to express their needs related to the care system increases the social visibility of children in the child protection system. By listening to what young people have to say, caregivers become more aware of the emotional dynamics between adults and minors, which can contribute to reducing social prejudice against children and young people in foster care and institutions, as exemplified by the Who Am I? competition. In a functional child protection system, the voices of empowered children and young people need to be amplified. Strengthening their capacity to express themselves and be heard facilitates the empowerment of young people and their process of becoming autonomous. Listening to young adults who are about to leave care can help professionals working in the foster care and institutional system to better understand what they need to prepare for an independent life, including their fears and potential stumbling blocks. The apps described in this chapter also provide professionals with up-to-date knowledge, help them understand their clients' feelings and thoughts, and aid them in taking joint action in an effective collaborative way to resolve their personal life.

These tools contribute to children's safety by providing them with quality and adequate information on important topics like independent living or communication with peers, parents and adults. It is important that young people were involved in collecting and analysing these data as research participants, such that their opinions were incorporated into the research, which also guaranteed that the apps would be easy for their peers to understand, like, and use. They said it was important to be able to express their views on difficult issues at the preparatory research stage and when an ICT-based product was developed along these lines, to be able to comment on it in a meaningful way at the testing stage. Their suggestions and requests for changes were acknowledged by the development teams and validated during the finalisation process. Testing was also extended to professionals, such that in all cases, they also indicated that both applications were a great help in their daily work and that they were looking for ways to use them. Participants stated that there was a need for wider use of the application, which is why the continued use of YounGo and Asszerteen in school social work is being considered. Because the development processes for both apps were participatory, they provided very important lessons on the involvement of children and young people in child protection situations. The results give us a better understanding of their situation and difficulties. The results indicate what type of information and help they need in the process of growing up. The results also show how they communicate with their friends and adults and in which situations they found it hard to express their emotions or opinions. A drawback, however, is that due to the projects' funding and time constraints, this involvement was very targeted and somewhat limited. Both apps must be updated with new content annually – for example, changes in the judicial system – and updating the YounGo app needs more funding. Table 8.2 summarises the benefits of innovations involving children and young people in research methods.

It is worth thinking about projects and service development in the field of child welfare and child protection that provide more time to recruit a team of children and young people, seek their views, involve them in development and testing, and put their views into practice. Two small-scale examples of this, however, clearly show that there are many benefits of listening to children's and young people's views, which are summarised in Table 8.2.

Table 8.2. Benefits of Innovations Involving Children and Young People in Research Methods.

Involving Children in Research Process	**Involving Children in Testing and Finalising Apps**	**Involving Children in Further Development of Apps**
Mapping their knowledge and opinion Clarifying their needs and notions about available support and services Giving them a chance to raise their voice Sharing information and new experiences Learning new skills and abilities (cooperation, collaboration Improving confidence and self-assessment Providing feedback about their experiences in the study	Finalising app content and design based on opinions of children and young adults Aspects of peer groups appear in app through participants (children and young adults), such that app is authentic and credible	Gaining relevant knowledge for developing child welfare and child protection services through credible participants New aspects for development Strengthens children's focussed attitude and approach of professionals and adult generation Involving children and young adults creates culture of participation in Hungary Goals for further development: Raising and hearing voices of children is inevitable In multiple phases, ask for their opinion during research and development process

Source: Original work based on Elek (2022).

Conclusions

This chapter outlined the experience of developing two applications and one thematically relevant video competition, with the aim of showing the gains and strengths that participatory projects can bring, including as a learning process for professionals. The outcomes indicate that participatory research among children and young adults can help the research process be more targeted, and precise if participants – in this case, children and young adults – are involved.

During the development phases of the YounGo and Asszerteen applications – i.e. design, implementation, testing and finalisation – the representation of young people's opinions was very prominent and they expressed happiness about participating in these phases. Both apps are primary preventive tools for mental health because they help users cope more effectively with everyday stress and problems by developing communication, life, problem-solving, cooperation and other skills, including those needed to become successful adults. All these skills are also much needed by professionals and can be put to good use in their daily work.

This chapter highlighted the advantages of participatory research among children. The participation of children improved the development process of these apps. Their participation clarified their needs and taught them how to express and act for themselves. The outcome of the Who Am I? campaign emphasised that participation gave them an opportunity to introduce their situation and raise their voice. The participants were open to this task and found their voice easily. The chance to share their thoughts about their life and opportunities helped decrease prejudice and generated a positive and authentic image about children and young people in the child protection system. In addition to improved self-confidence and self-assessment, the participants learnt new skills and broadened their knowledge. The results show that participatory research can help define the special needs of children and create a more targeted and efficient child protection system.

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Chapter 9

Using Community Art to Encourage Children to Participate in Discussions About Violence

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Abstract

Increased emphasis is being placed on developing creative approaches when working with children in research settings, especially with sensitive research topics like violence against children. Community art is a social form of art that gives artists the opportunity to work in collaboration with the public, with the aim of highlighting and addressing specific social issues. This chapter reflects on an art exhibition organised in Reykjavík called *Wishes of Icelandic Children*. The project was a collaboration between artists and children. The aim of the chapter is to present how an art exhibition may put violence that children experience into focus and encourage attendees to reflect on the subject by looking at descriptive pictures and texts from the Convention on the Rights of the Child and then writing comments about their thoughts and feelings. The research questions are: How do children express themselves about sensitive topics such as abuse and violence? Can community art enable professionals to better support increased participation of children in discussions about abuse and violence? This study involved a qualitative thematic analysis of comments written by children after having seen the exhibition. Three students took part in the analysis process as co-researchers. The exhibition was successful in creating a platform where children could express themselves on topics concerning abuse and violence. Many comments expressed an ardent desire to end violence in society, especially emphasising bullying, which can limit young people's capacity to feel safe and express themselves.

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Keywords: Children's participation; community art; photography; community violence; qualitative thematic analysis; co-researchers

Introduction

Visual art is a form of artistic expression that has long been used to address social injustices and inequalities and call for societal change (Butler, 2001; Huss & Sela-Amit, 2019; Phelps, 2017; Visser-Rotgans & Marques, 2014). Addressing social issues and presenting them through artistic lenses help bring attention to the position of specific groups while also calling for increased attention to the community, potentially channelling discussions towards social reform (Campana, 2011; Capous-Desyllas & Bromfield, 2020; Visser-Rotgans & Marques, 2014). Community art is a visual art form in which artists work collaboratively with citizens to shed light on a particular social situation or challenge facing society. The process of participating in the artwork is often considered more significant than the product. This is an interesting method that provides participants with opportunities to take an active role and express their opinions about issues in the environment, sometimes sensitive ones, and create a more participatory process (Huss & Bos, 2022). Using art in this way sheds light on the diversity of communities and cultures. Although it does not necessarily create substantive change in society alone, it does change perceptions, increase understanding and promote discussion in the community about what could be done better. With community art, it is possible to create an important space for children to be active participants and express their thoughts and experiences (Huss & Bos, 2022; Huss & Sela-Amit, 2019; Visser-Rotgans & Marques, 2014). Knowledge and perceptions about children and their place in society have developed from children being viewed as vulnerable and in need of protection towards being seen as social agents with rights. The role of the child as a social actor is grounded in theory about children's competence (Aldridge, 2017; James et al., 2012; Mayall, 2009). This is supported in legislation concerning children's rights and well-being (Child Protection Act No. 80/2002, 2022; United Nations Convention on the Rights of the Child [UNCRC], 1989). Accordingly, although welfare service practitioners and researchers have increasingly sought to involve children as participants, the views of marginalised children on various sensitive issues are still not commonly heard (Brady et al., 2012; Collings et al., 2016; Garcia-Quiroga & Agoglia, 2020; Kennan & Dolan, 2017). One reason why children are not included when sensitive issues are being discussed is, according to professionals, the lack of tools and methods to discuss sensitive issues with children (Martins et al., 2018; Mossige & Backe-Hansen, 2013; Vis et al., 2012).

By using appropriate tools and methods to increase children's participation in participatory research, arts-based methods such as photography have increasingly been used to involve children in a discussion that concerns their lives and circumstances, especially if the issues are defined as sensitive. These methods can empower children and provide an appropriate environment to participate in discussions about difficult feelings and experiences (Desmond et al., 2015; Drolet et al., 2022; Huss & Bos, 2022; Pavarini et al., 2021). Therefore, this study analysed data created by children who visited an exhibition titled *Wishes of Icelandic Children*. The aim was to examine whether community art can serve professionals when engaging children to participate in discussion on violence. The following research questions were addressed: How do children express themselves about sensitive topics such as abuse and violence? Can community art enable professionals to better support increased participation of children in discussions about abuse and violence?

Ways to Increase Children's Participation

With the growing adoption of the UNCRC, nations around the world have confirmed that children's participation is a necessary component of the development of society. The aim of the UNCRC was to safeguard the human rights of children and ensure their participation in issues that concern them (UNCRC, 1989). Children's participation is defined as their right to participate and receive support in making decisions that relate to their lives and conditions, while simultaneously emphasising and respecting their need for protection (Gallagher et al., 2012; Mason, 2008; Pölkki et al., 2012). Critics of children's participation have raised doubts about whether such ideas exercise appropriate caution and whether children are capable of participation (Daley, 2015; Hammersley, 2017; Jensen et al., 2020; Moore et al., 2021; Taplin, 2020). Many professionals echo these criticisms, with reactions that often seem to be informed by the idea that children are defenceless and volatile (Mossige & Backe-Hansen, 2013; Sandberg, 2018). Other researchers have argued that protecting children does not conflict with encouraging their participation; such support entails creating conditions that are conducive to participation with methods suitable for children (Brady et al., 2012; Fern, 2014; Jensen et al., 2020; Mossige & Backe-Hansen, 2013; Sandberg, 2018). Despite a growing knowledge base regarding work with children, professionals have been criticised for failing to adopt diverse professional methods, which often results in difficulty relating to children (Brady et al., 2012; Donnelly, 2010; McLeod, 2007). Applying relevant professional methods involves, among other things, creative ways to encourage children's participation (Capous-Desyllas & Bromfield, 2020; Morrow, 2008; Phelps, 2017). Professional methods entail offering children support that is suitable for their developmental stage. It is important to create conditions and an environment that inspire and encourage children on their terms (Kennan et al., 2018; Lesson, 2007). An emphasis is placed on applying proven methods when working with children, and professionals are increasingly encouraged to adopt such practices, use creative approaches and appeal to children's visual perception to better relate to them (Denov & Shevell, 2019; Munro, 2011).

Children as Key Informants About Their Lives

Munro (2011) highlighted that children are key informants about their lives and the impact of any problems on them. Children's perspectives and experiences in relation to difficult situations provide practitioners and authorities with a deeper understanding of the problems children deal with; this can produce new opportunities for reform (Bruce, 2014; Hill, 2006; Mossige & Backe-Hansen, 2013). It is important to open the discussion about abuse and violence and involve children in that conversation. Abuse can cause serious developmental complications and disrupt the relationship between parents and children. Abuse has a broad meaning and can refer to sexual abuse, mental abuse or bullying; it can also entail witnessing violence committed against others (Freysteinsdottir, 2012; Lloyd, 2018). Violence can negatively affect children's health, well-being, education and relationships with friends and family; moreover, it is often a well-guarded secret in families (Blair et al., 2015; Kristinsdottir, 2014; Lloyd, 2018; Mandara et al., 2021).

Icelandic Context

Iceland is still an ethnically and culturally homogenous society as of 2021. Most inhabitants, about 85%, were born in Iceland and speak Icelandic, which is a dominant language at all levels of society (Statistics Iceland, n.d.). How children are empowered to participate takes various forms in different cultural and legal contexts in each country. In Iceland, the declared role of statutory social services is to create an environment that supports the well-being of children and their families; it is responsible for providing alternative support for children who receive insufficient care from their parents and helping families meet their children's needs (Social Services Act No. 40/1991, 1991). The Child Protection Act No. 80/2002 (2002) and Children's Act No. 76/2003 (2003) forbid the use of violence of any kind against children. It is, therefore, clear that any kind of violence against children is illegal in Iceland.

It has been difficult to achieve widespread public recognition of the problem of domestic violence against children, due to the indirect effects of the violence. But its recognition is considered by many to be a prerequisite for working on prevention and improving treatment and resources for victims of violence. Research results have indicated that children often show signs of discomfort if they experience domestic violence (Einarsdottir et al., 2004). Between 2,000 and 4,000 children experience domestic violence every year in Iceland. Using the lower estimate, only 14% of these cases are reported to child protection authorities (Arnardottir, 2011).

The UNCRC (1989) drafted two articles dealing with violence. Article 19 asserts the right of children to protection against all forms of violence and neglect, and Article 34 insists on the protection of children from sexual violence. Following the UNCRC (1989) and its subsequent 2013 ratification in Iceland, the legal position of children in Iceland has improved with an emphasis on strengthening the status of the child. One element is ensuring the right of the child to participate, which is based on the idea that active participation promotes children's involvement in a democratic society (Fridriksdottir & Gisladottir, 2015). A child's right to participate is particularly important for children in precarious social conditions (Martins et al., 2018). Elevating the voices of children in these situations strengthens their identity and provides them with the experience of enjoying respect and human dignity (Eriksson et al., 2013; Kristinsdottir, 2014; Lundy, 2018).

In 2014, the city of Reykjavik launched a campaign against domestic violence in collaboration with the police, the Women's Refuge and the Health Service. The cooperation among these organisations is intended to ensure the safety of city residents in their homes, provide better services to victims and perpetrators and improve the situation of children living with domestic violence. Here, domestic violence is defined as violence against a person by those close to them. The violence can be physical, mental, sexual or financial and includes the use or threat of force. If children are at the scene of domestic violence, a child protection worker and worker from social services must be informed of the situation and called to the scene immediately (Gunnarsdóttir, 2019; Ríkislögreglustjóri, 2018).

The event *Wishes of Icelandic Children* took place in 2014 on the 25th anniversary of the UNCRC and included a photography exhibition organised by Barnaheill – Save the Children in Iceland (Barnaheill, 2014). The exhibition was held in the capital region, but also in various smaller towns around Iceland. The exhibition of photographic art can be defined as community art in light of its goals of raising awareness of child violence, abuse and poverty in Icelandic society and generating discussions on the issue. It featured images of children accompanied by paragraphs from the UNCRC, along with text fragments based on the experiences of Icelandic children who had been subjected to abuse. The exhibition was aimed at children, but professionals working in compulsory schools were especially encouraged to attend the exhibition with their students. Additional instructions were developed to achieve the aims of the exhibition and support professionals in exploring the experiences of children who attended. Concurrently, a digital space was created for child guests that allowed them to express their experiences and make their voices heard on these sensitive topics of children undergoing poverty and violence, as stated in Article 12 of the UNCRC (1989). Children thereby had the opportunity to express themselves and influence other people visiting the exhibition. Having the possibility to see their comments in the digital space of the exhibition became an important part of children's awareness about violence and abuse, and it facilitated their active participation in a democratic society.

Methodology

This study used a qualitative research method. The study design was participatory, such that data came from written notes in the form of wishes from children who visited the art exhibition, and children participated in the data analysis process. The exhibition was interactive. Children came and looked at pictures and then created a space to make their voices heard. The children's messages were then used to highlight children's experiences and ideas in an important conversation about violence, while simultaneously creating opportunities to gather data that could be viewed and used to better understand the effects of violence on children and how to work against violence. These data came from the exhibition, where children provided input by writing down their wishes, including their feelings and thoughts after they observed the artwork about violence and abuse. The data seemed be promising for this research project. The study was conducted in 2016 and 2017. The goal was to examine whether community art can engage children in discussions on violence and prompt creative ways to talk about the impact of violence and abuse against children.

The participants in the study were preschool and compulsory school children who attended the exhibition *Wishes of Icelandic Children* and documented their wishes on notes that were stored in the exhibition space. Children in preschool are 2–5 years old, and most of them have not yet learnt to write. Children in compulsory schools are 6–16 years old, and most of the wishes came from that group of children. The exhibition was mainly targeted at children and their teachers, and although members of the public were also welcome to attend, they were not asked to write notes or wishes. Many children wrote their age on the note, though not all of them did. Of those who noted their age, the youngest was 3 and the oldest was 16.

The research data consisted of written notes by children who attended the exhibition *Wishes of Icelandic Children.* The exhibition was open for 2 years, between 2014 and 2016, and data collection took place throughout that period. After viewing the exhibition, the children were encouraged by their teachers to write a note in the form of a wish. They hung the notes on a ‘wishing tree’ or placed them in a box inside the exhibition area. In this way, the exhibition entailed an interactive process intended to further expand on the children’s experiences. A total of 1,751 wishes were collected. Of these, 314 were deemed unusable as data because it was impossible to read the wishes. It was difficult to determine whether each child wrote only one wish, and some notes had two wishes written on them. It is likely that the youngest children had received assistance writing down their wishes.

Data Analysis

We applied thematic analysis as described by Braun and Clarke (2013), following the procedures of coding the messages by identifying and reporting themes, then highlighting the meaning of data. Three young co-researchers aged 16 or 17 from the Child Welfare Youth Council attended the analysis process and contributed as co-researchers, offering their perspectives regarding the interpretation of the data. The co-researchers’ role was to read the wishes with the researchers and participate in making coding decisions. Together, we produced descriptive and semantic codes, categorised the themes and applied the coding criteria to the messages to include or exclude them in the identified codes (see Fig. 9.1).

Wishes were included if they related to issues of violence and therefore to our aim and questions. We excluded wishes that we could not read or did not seem related to our study. After reading all the included wishes repeatedly, we started

Fig. 9.1. Analysing the Wishes.

the coding the wishes on small post-it notes, one wish to each note. The notes were in variety of colours. We used one colour for each code and sought to categorise similarities and differences in the wishes. The next step was to identify categories and themes that emerged in the data, which were classified in view of the research questions. In this chapter, we introduce three themes related to 630 notes.

Findings

The wishes were diverse, but most reflected children's experiences or ideas of violence. The sheer number of wishes (n = 1,437) suggests that children had a strong need to express themselves about their experiences and attitude despite the difficulty and sensitivity of the topic. They appreciated the exhibition and the opportunity to express themselves. One child communicated this appreciation by wishing 'that every day would be like this one'.

The children's experiences sometimes manifested as wishes for their lives to be different, whereas other wishes involved dreams of transforming into an animal or gaining the ability to fly. Some wishes suggested that the children had suffered serious abuse. One child wrote: 'I wish he had never undressed me and touched me'. Many of the wishes expressed a powerful desire to end violence in society. Other wishes called for stronger measures against bullying and that it should be eradicated so that everybody would be allowed to express themselves, without being criticised or bullied.

Using thematic analysis, children's wishes were grouped into the following dominant themes, which we associated with either abuse or neglect. Of the 1,437 wishes, 630 were related to themes of ending abuse and neglect: (a) being spared from experiencing violence ($n = 258$), (b) being allowed to be oneself ($n = 114$) and (c) insecurity and lack of care ($n = 258$).

We analysed another category – children wishing to be allowed to express themselves freely – connected to the topic of children's rights to their identity, non-discrimination and participation in social life.

The messages in these thematic groups indicated that the children were aware of violence in society and its effects on children. Some messages suggested strongly that the person who wrote them had personally experienced abuse or neglect, which can be one manifestation of abuse. Other messages indicated that the children were aware of violence or neglect in their environment and wanted it to be prevented in one way or another and that they not be subjected to discrimination.

Being Spared From Experiencing Violence

The children communicated a clear wish not to experience violence in their community, in their family, among friends or personally. Many wishes involved worries about global peace. Many children wished that wars did not exist and that no one should have to be subjected to that level of threat, as exemplified by three notes:

> I wish there were no wars, only peace on EARTH.
>
> I wish the world could be a good place for all.
>
> I wish that all violence against children would be erased.

The wishes expressed the children's view that violence was terrible and that the world's resources were unevenly distributed. Many people suffered injustices. Several wishes stated sentiments like 'this disgusting violence should end' and 'the world would become more just'.

Figs. 9.2 and 9.3 are from the exhibition *Wishes of Icelandic Children* (Published with permission from the photographer, Asta Kristjansdottir, in 2016). The figures are connected to the UNCRC (1989) Articles 19 and 34, which state that children have the right to protection against any physical, mental, and sexual violence, abuse, indifference, and neglect inside and outside the home.

The children communicated the wish not to be exposed to violence and conflict in their families, as can be seen in the following three notes:

> I wish my mom would stop shouting.
>
> I wish I didn't have such an angry mom.
>
> I wish no one would fight and I wish we were all good friends.

Three other wishes had to do with distress from witnessing alcohol use in the home:

Fig. 9.2. I Wish I Were a Princess. 'It Is Also Possible to Hit Children With Words. It Hurts a Lot' (6-Year-Old Child).

> I wish mom and dad would stop drinking.
>
> I wish dad would stop drinking and start talking to me again.
>
> I wish mom and dad wouldn't fight when dad drinks.

Some children wished that their siblings would refrain from using violence against them. One child wrote:

> I wish my brother wouldn't be so violent and he'd be a good boy.

Another wished:

> That … my sister would stop teasing me and calling me an idiot.

Fig. 9.3. I Wish I Could Fly Away. 'I Told Him to Stop, but He Didn't' (13-Year-Old Child).

The exhibition gave rise to thoughts about bullying and violence experienced by the children. Some of these children wrote:

> I wish I wasn't left out in school.
>
> I wish that no one could hurt me.

Being Allowed to Be Oneself

Many wishes suggested that children felt hindered in being themselves or they felt that others were prevented from being the way they wanted. This theme was often associated with bullying. One child said:

> I wanted the kids to have fun with me. I feel bad at school.

The children wished 'there was no bullying' or 'that no one would have to experience bullying or violence'. They were, therefore, not only thinking about freeing themselves of bullying but also freeing others. These thoughts were reflected in two wishes:

> I wish that bullying did not exist.
>
> I wish that we could stop bullying.

One child sent the following message:

> Though something is a joke it can still hurt someone.

Physical appearance was also a common theme among the children, with some wishing to be accepted as they are. They wished that people 'would stop judging people based on their appearance', though a few children expressed that they wanted to live up to society's unwritten standards concerning appearance. Three notes contained the following messages:

> I wish I wasn't so fat.
>
> I wish I was skinny.
>
> I wish I was beautiful.

Some children wished that everyone could receive respect, regardless of appearance:

> I wish people would show respect to everyone no matter what they look like.

Other children wished that everyone would look the same to avoid violence and bullying:

> I wish everyone could be like everyone else.

Insecurity and Lack of Care

Some of the children's wishes indicated insecurity, difficulty in connecting with others and a lack of care. Many children wished they had a better or stronger connection with their parents.

One child wished for a life in which they would no longer have to always 'miss mom and dad'. Another wished they could 'spend time with mom all the time', whereas other wishes indicated a desire to have stronger bonds with their parents or visit them more frequently. Four participants left these wishes:

> I wish I could have a good and healthy relationship with my father.
>
> I wish I could go home to mom.
>
> I wish I could meet my real parents.
>
> I wish I could meet my father.

Some wishes came from children who had lost their mother or father. The following was written on two notes:

> I wish dad was still alive.
>
> I wish mom could come back to life.

The art of the exhibition seemed to provoke a variety of emotions and thoughts in the children, which often were linked to a desire for a better life and better world for themselves and others.

Discussion

It is important to keep in mind that the findings of the study are only based on the wishes of children who chose to write notes after they had attended the exhibition *Wishes of Icelandic Children*. Therefore, it is difficult to assert that the wishes speak for the experiences of all children who viewed the exhibition. The exhibition was well attended by students, many whom arrived under the supervision of teachers from many Icelandic compulsory schools. It is likely that the socio-economic status of attendees was more diverse than is generally the case for art exhibitions.

The findings of the study suggest that community art can be used to include children's voices on issues that they confront in their environments. Using participatory methods that involve visual art can be a way to access important knowledge and experiences of children, especially marginalised children, regarding violence.

The children's messages indicate that the exhibition achieved its aims. The diverse wishes describe the children's experiences, often transmitting a clear and direct meaning. Many children seemed to have reflected on the content of the exhibition and sought to communicate their thoughts and feelings honestly in response. Some children wished for the end of violence, which highlights that those children are aware of the devastating impact of violence and shows that they can discuss the issue on their own terms (McLeod, 2007; Vis et al., 2012). Violence can be well hidden (Blair et al., 2015; Kristinsdottir, 2014; Lloyd, 2018), and the wishes indicate that some children who visited the exhibition had suffered violence of some kind. In this way, community art is important and can increase people's awareness of violence and strengthen the discussion of this issue (Lloyd, 2018). The children found it important that individuals are allowed to be themselves, free from teasing and bullying due to being different from others. These wishes suggest the negative emotional impact resulting from experiencing or witnessing bullying, which is in accordance with previous findings relating to the far-reaching and serious impact of violence on children (Lloyd, 2018; Mandara et al., 2021). Therefore, it is important to talk to children about the consequences of being victims of bullying and collaborate with them to change the culture of schools and enhance the value of friendship in the school community.

Our findings are in line with other research findings that children are ready to participate, discuss and reflect on difficult issues such as violence. If they seek to express their thoughts regarding these issues, it is important to create platforms through which they can feel safe communicating their thoughts and feelings. Children's position in society is strengthened by listening to and considering their wishes. In this way, children can be acknowledged as important participants in shaping society (Gallagher et al., 2012; Lundy, 2018; Mason, 2008).

Based on the number of wishes received from the children and how they describe their feelings and thoughts, we conclude that community art can be used as a creative tool by practitioners to increase children's participation and talk about sensitive issues such as violence. It is important to introduce these kinds of methods to practitioners to support them in identifying injustices and challenging situations faced by certain groups, with the aim of increasing the public's understanding and awareness of violence. More open discussion is needed to help prevent abuse, optimise outcomes for children and improve the situation of children in society.

This research was a pilot study combining participatory research with a multifaceted collaboration involving an artist, social organisations, children who visited a certain art exhibition and children who participated with the researchers in reading and analysing the study data.

Our results indicate that children are aware of different manifestations of violence. Professionals who work with children, like teachers, could be trained to offer advice on sensitive issues using these methods and then invite children to participate in solving the problems in their environment. Such solutions could be used in classrooms and school community to improve the school's atmosphere, children's environment and children's lives.

Limitations

We have limited knowledge about the participants who wrote the comments. The researchers received access to the exhibition guestbook to extract information regarding the participants and their origins, but the guestbook lacked information concerning the total number of visitors to the exhibition. Another limitation is that the data consisted not of continuous text but rather messages written as individual sentences, which proved relatively difficult to contextualise. Whether data between 2015 and 2016 are still interesting and relevant today might be questioned; we concluded that they were important. However, a great strength of the study is the sheer number of children who expressed their thoughts following the exhibition by writing down their wishes.

Conclusion

Based on the number of wishes received from the children and how they describe their feelings and thoughts, we conclude that community art can be used as a creative tool by practitioners to increase children's participation and talk about sensitive issues such as violence. It is important to introduce these kinds of methods to practitioners to support them in identifying injustices and challenging situations faced by certain groups, with the aim of increasing the public's understanding and awareness of violence. More open discussion is needed to help prevent abuse, optimise outcomes for children and improve the situation of children in society.

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Chapter 10

Left-Behind Adolescent Co-researchers' Participation in Studying Transnational Families

Éva László, Alina Bărbuţă, Viorela Ducu, Áron Telegdi-Csetri and Maria Roth

Abstract

The topic of parent migration and its effects on the family environment has become a focus of moral dilemmas in East Europe for the last three decades. Children have been portrayed as social orphans and parents working abroad as neglectful parents. Today, with more evidence from research and experience, the impact of parental migration is much more comprehensive and nuanced, recognising its noxious or even harmful but also possibly empowering effects. This chapter reflects on the involvement of left-behind adolescents as co-researchers in a study of transnational families. It acknowledges the agentic role of children (often automatically labelled as victims of neglect), amplifies their voices to inform existing data on the impact of parents' departure to work abroad and identifies directions for intervention that might strengthen families.

The research is an integral part of CASTLE – Children Left Behind by Labour Migration, an ongoing project (June 2021–December 2023).[1] This chapter presents the research collaboration experience with 12 co-researcher

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[1] Details are presented on the project website: https://fspac.ubbcluj.ro/castleaction/en. The project partnership is formed by: Babes-Bolyai University (coordinator), Terre des hommes: Swiss and its delegations in Romania (project initiator and manager), Moldova and Ucraina, Academy of Economic Studies of Moldova, and Ukrainian Institute for Social Research

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adolescents with previous left-behind experiences, originating from Moldova and currently residing in Romania. The co-researchers participated in all stages of the research process: training, design of data collection, recruitment of research participants, data analysis and dissemination of results. Taking co-researcher roles had an empowering effect on adolescents, who learnt how to express their views on the topic, voiced their experiences about the emotional costs of being left behind by their parents and reflected on sensitive issues like separation of family members and violence in the family.

Keywords: Co-researchers; left-behind children; participatory research; labour migration; transnational families; social orphans

Introduction

In the context of globalisation and increased international labour mobility, many children are growing in transnational families. In these families, certain members live away from home in another country for long or short periods, yet the family retains a sense of collective welfare, unity and familyhood (Bryceson & Vuorela, 2002). The research discussed here involved transnational families in which the parents are away from their family to work abroad, leaving their children at home.

Many families in Romania, the Republic of Moldova and Ukraine (the countries involved in this project) are seriously affected by labour migration. In the Republic of Moldova, one of the poorest countries in Europe, working abroad and living in a transnational family to ensure the family's livelihood has become an integral part of everyday life, with around a quarter of the country's population living abroad (IOM, 2021; Vremiş & Vladicescu, 2020). Approximately 3% of all children in the Republic of Moldova were registered as separated from their parents in 2020. Many are from rural areas, and the main reason for separation is the migration of their parents (Sandu et al., 2022). In Ukraine, according to the Ministry of Social Policy (2018), 3.2 million worked permanently outside the country. It should be mentioned that these data reveal the migration context prior to Russia's aggressive invasion of Ukraine, in February 2021. With the escalation of the Russian–Ukrainian conflict, outbreak of war and change in national priorities, data collection related to labour migration issues could not continue in Ukraine.

Migrant parents are often seen as neglectful of their left-behind children (LBC), who are often termed 'social orphans' or in the case of parents migrating to mostly Western Europe, 'EU orphans' or 'Euro-orphans' (Iosim et al., 2022). Media have highlighted possible extreme negative cases of parental migration (suicide of children, serious crimes etc.) involving LBC, creating and maintaining a moral panic (Cojocaru et al., 2015). Today, we have a more nuanced picture of the impact of parental migration, based on empirical and research evidence, showing that communities, families and family members respond to and manage parental absence very differently. Both parent migration and coping with it are complex, multifaceted and context-dependent phenomena (Démurger, 2015).

It is undisputed that parental labour migration abroad is a worldwide phenomenon that considerably shapes and changes families' inner dynamics, roles, tasks distributions and responsibilities regarding children's education, health and well-being (Antia et al., 2020; Deng et al., 2022).

Researchers also largely agree that the effects on LBC's mental health are often negative, with children presenting vulnerability regarding mental health problems such as anxiety or depression (Fellmeth et al., 2018; Tomşa & Jenaro, 2015), health issues (Botezat & Pfeiffer, 2020), risk-taking behaviour such as abusing drugs or alcohol or breaking the law, and increased exposure to violence or bullying (Baudeau et al., 2021). In the literature, LBC are categorised as vulnerable children who are temporarily separated from the care and protection of at least one parent and at risk of significant emotional costs that affect them for shorter (Botezat & Pfeiffer, 2020) or longer (Iosim et al., 2022) periods. In their literature review, Antia et al. (2020) found that researchers in the Americas and South Asia have registered only negative changes, but in Eastern Europe, studies found health and well-being indicators for LBC in Georgia and Moldova that did not significantly differ or were even better compared to children of non-migrant parents (Cebotari et al., 2018). Transnational families may improve their economic situation, which might contribute to an increased sense of autonomy, independence and responsibility for LBC (Juozeliūnienė & Budginaitė, 2018; Pantea, 2011); stronger connections between siblings; and increased chains of support between older and younger children (Juozeliūnienė & Budginaitė, 2018).

A significant barrier to designing and implementing adequate child protection frameworks that mitigate the negative consequences of labour migration on children stems from insufficient research and understanding of the phenomenon and its impacts. Thus far, the scientific literature on LBC in Romania, Moldova and Ukraine has focussed on their well-being and the role of parents in transnational families from an exclusively care-oriented perspective. Hence, these children have been predominantly seen as social orphans, and their views have remained largely invisible (Fresnoza-Flot, 2018).

Studies that examined the participation of children in decisions related to migration, especially in the case of LBC with parents working abroad, showed that children's opinions are rarely and limitedly considered in the lives of transnational families (Deng et al., 2022). The voices of children usually are not heard by adults because they underestimate their level of competence (Hoang & Yeoh, 2015; Pantea, 2011).

Participation of Children in Transnational Family Research

Understanding children as agents of transformation in their societies and communities is a crucial part of discerning how childhood relates to the surrounding society, its structures, and cultures and developing strategies for ensuring children's participation (Corsaro et al., 2009; James & James, 2008). Participatory designs attempt to involve these stakeholders in the design process.

Children are important stakeholders because they are the experts in their life experiences (Bergström et al., 2010; Mason & Danby, 2011) and hold the right to participate and be involved in decisions affecting their lives (Lundy et al., 2011; United Nations, 1989, Articles 12 and 13).

By giving children the role of researchers, co-research can be defined as a method that engages participants in an epistemological research process (van Doorn et al., 2014) by accessing three interdependent and important resources: (a) children can use their network to access peers or key people; (b) conversations between peers generate different content than conversations between a participant and researcher; and (c) it enables listening to others and hearing different people talk about the same subject.

The fundamental aim of including children as co-researchers is to uncover children's views and ways of operating and acting regarding their daily problems. The umbrella concept of children as co-producers can define and describe all roles that children can have in research – as a subject, participant and data producer. Many studies showed that co-researching with children is helpful to gather contextual knowledge, and besides the active component, the co-producing role also includes two important aspects: the passive and reluctant sides of children. Hence, if they only participate as subjects in research, it is more difficult to access information from these two sides (Jacquez et al., 2013).

Assuming an approach that gives children the status of co-researchers involves first detaching from the (implicitly adult) scientific perspective and highlighting the children's views on the studied issue. In most cases, identifying the child's position involves a shift from the standard research methodology to focus on an experimental design that is closer to the children's world. The objective of this orientation is to examine children's and youth's views, their ways of operating and acting, and the data they produce. It includes listening to children's mixed signals and information through multiple methods and analysing their experiences, views, actions, values and ways of operating (Bradbury-Jones & Taylor, 2015; Ødegaard & Borgen, 2021).

When studying a social problem through the lens of children's perspectives, we need to pay special attention to how the subject, agency, power and influence are intertwined. How researchers perceive the status of children has an influence on their choice of methods. Children's experiences and thoughts offer valuable input to the design process to ensure the product fits their needs (van Doorn et al., 2014). For that aim, children need to be involved in the research project from the start of the design process.

Considering the fact that separation of children from one or both parents significantly changes their lives, the involvement of children as co-researchers in studies that address the issue of LBC by parents' labour migration is even more necessary; as previously mentioned, empirical data indicate that children are not involved in the migration decision-making process (Deng et al., 2022).

Methodology

CASTLE – Children Left Behind by Labour Migration is an ongoing project in which a research team in Romania is developing an action-research model to support the Republic of Moldova and Ukraine in improving their child protection framework and migration and mobility policies to reduce risks for LBC in transnational families. During these research activities, the situation of LBC is being analysed from the perspective of risks for children and their rights, highlighting their rights to safety and security, to grow up in a family and to participate in decisions affecting their lives.

During the design process, a participatory research design was adopted by the project team as the most appropriate method for the purpose and objectives of the CASTLE project based on a common goal: the inclusion of all group members and an approach based on rights and strengths.

Participants were made aware that the common goal was to hear the voices of children and ensure they are shared with stakeholders, including policymakers. The research results are meant to guide policies and practices appropriate to the needs of the community, with an empowering effect on the young people involved (Cahill, 2007; Pant, 2014).

Inclusion was ensured through collaboration – offering support to those most affected by the activities – in all stages of the research project for all participants: children, adolescents and adults who are members of transnational families and caregivers. This offered more power and influence on their lives (Pain, 2004; Pant, 2014). The activities were based on a strengths approach, with participants being seen as competent and active agents and experts on their experiences (Harvey, 2014).

Ethical Considerations

Research ethics have been conceived mainly as a question of risk management (Graham & Fitzgerald, 2010). Ethical procedures need to be viewed as risk management, and a beneficial research practice is to stimulate continued debate about how to work ethically in social science research when children are co-producers of data.

In agreement with the co-researchers, we applied the following fundamental ethical research principles involving children (based on the International Charter for Ethical Research Involving Children; Graham et al., 2013):

- The principle of respect for human dignity. This was ensured by carrying out the following actions: A child- and adolescent-friendly work atmosphere and procedures were created; consent forms and information sheets were provided to all co-researchers; a proper justification for the involvement of vulnerable persons was presented, starting from the aim and objectives of the project; and the principles of confidentiality and collegiality were observed.

- The principle of utility and benefit. The usefulness of this principle is reflected by the need to support transnational families by providing evidence-based policy recommendations with a representation of children's view.
- The principle of precaution (protection from harm, informed and ongoing consent). This occurred by carrying out the following actions: The research project team conducted a careful assessment of predictable risks and burdens in comparison with foreseeable benefits to the participants or others; proportionality was established between the risks facing research participants and the potential benefits of the research to children. Hearing about others' sensitive experiences regarding separation from parents and its consequences can result in distress (Gibson, 2007). Safety measures were developed to protect the well-being of young co-researchers, including opportunities for supervision, and mentoring by experienced researchers and psychological support from counsellors. All participants had the right to voluntary participation and to withdraw without any negative consequences.
- The principle of justice. This was ensured by carrying out the following actions: All co-researchers were informed regarding the methods used for handling personal data; justification for requesting and obtaining their data; duration of data use and storage; guarantees concerning the appropriate use of data and fair remuneration via vouchers equal for adult and minor co-researchers, as suggested by Bradbury-Jones and Taylor (2015).

Recruitment of Co-researchers

Regarding the young co-researchers, inclusion criteria were established by the international team according to origin (Republic of Moldova or Ukraine), family history (one or both parents went abroad for work and the child remained in the country of origin), age (10 years old or older) and basic ethical provisions (voluntary participation, parental consent). Next, each national team discussed the means of creating its group of co-researchers with whom they would work during the project, considering access to potential co-researchers, the expertise of the national team of researchers, and the specific aspects of each country.

Taking the leading role for the other partners, the Romanian team initiated a model for working with the adolescent co-researchers, with the following requirements and specificities. Because cooperation with co-researchers is long term, requiring many meetings and continuous contact, the Romanian children's co-researcher team had to be composed of children who were from one of the two partnering countries (Moldova or Ukraine), were staying during the project in Romania, were accessible by the Romanian research team and had experienced left-behind status (one or both parents working abroad) for at least six months during their stay in their home country. The eligible age range was 14–17 years and, at the time of recruitment, participants had to be enrolled in a Romanian high school and be able to communicate in Romanian language.

Informing and inviting potential adolescent researchers occurred in two ways. First, formal invitations were sent to the management departments of schools in

Romania where children from Ukraine and Moldova were enrolled. Second, co-researchers were recruited through the informal networks of the research team (fellow researchers and volunteers from the Republic of Moldova living in Romania helped with most contacts). No other selection procedures were adopted to recruit co-researchers. All children who wanted to participate and met the eligibility criteria were accepted. A consent form signed by the teenager and at least one parent was required.

The co-researcher team members were seven girls and five boys who met the mentioned eligibility criteria, all of them from the Republic of Moldova and currently studying in Romania. Seven of them, one boy and six girls, remained involved throughout the research process, contributing to at least three phases of the project. All had the experience of being left behind in their home country and then migrating themselves, leaving families behind in Moldova.

Results and Discussion

In the following sections, we present and analyse the work carried out with the teenage co-researcher group based on the 6-stage model used by Fløtten et al. (2021): preparatory work, research design, recruitment, data collection, analysis and interpretation, and dissemination indicates the number of adolescents involved in each phase.

Preparatory Work and Training With Co-researchers for Participatory Research

Co-researcher's training is a continuous activity, involving professional support throughout the project from research design to dissemination and action-plan design (included in the CASTLE project). The frequency and length of the training meetings and the methods used should be congruent with the children's developmental level and competencies (depending on age, previous experience, schooling and special needs; Bradbury-Jones & Taylor, 2015). Our adolescent co-researchers lacked any previous research experience, so their initiation meant a slow 'dosing' of information adapted to their level of interest and involvement. The training plan featured six modules: (1) introduction (familiarisation and clarification of the topic); (2) research design (with an emphasis on discussing the topics of the interviews planned to be applied with other children left behind and their caregivers; preparing the interview guides for left behind children and their caregivers); (3) literature analysis (from searching for to analysing materials like studies, official documents, models of interventions, or campaigns); (4) data collection (interviewer skills, management of difficult situations, using educational videos and role-playing games); (5) analysis of qualitative data; (6) transposition of research results into actions for change.

The sanitary security provisions (because of the COVID-19 pandemic) compelled us to organise the first meeting online. The programme involved two modules. The first module focussed on getting to know the participants, introducing the project and, thus, becoming acquainted with the meaning of participatory action research. At the end of the module, each participating teenager decided to continue the work in Module 2 (preparing the research design). In the periods between group discussions, individual discussions were held with co-researchers online or via telephone conversations. The training had 4 sessions, with 12 adolescents participating in the first session and 7 in the following 3 sessions.

The advantage of online sessions was that adolescents living in different towns could easily participate. The disadvantages were caused by internet connection problems, the lack of a private space for the young people and the absence of personal connection.

Research Design

The research design, with a focus on research topics and the interview guide, was discussed in the second module, with the participation of all 12 co-researchers. Adult and adolescent co-researchers worked together, in small groups, guided by hand-outs prepared by the research team. The ideas, comments and proposals regarding the study design were finalised together (researchers and co-researchers). The teenage co-researchers worked intensively to explain the discussed topics from a child's point of view and develop the children's interview guide. The adolescents pointed out specific issues worth exploring in individual interviews, especially with teenagers, rather than in family interviews. One issue is secrets they might keep from their parents, whether secrets with a protective purpose that they think are necessary to protect the distant parent from problems at home or secrets of teenagers (smoking, skipping school, neglecting tasks etc.) that protect them from certain unwanted consequences.

At the end of the module, each participant confirmed their interest in the programme. Specifically, the co-researchers expressed their interest in the interpretation of the data and their transposition into models of change.

Recruitment of Study Participants

To prepare for the recruitment of children for interviews, a draft of the invitation letter and information was elaborated by two researchers, and seven of the co-researchers contributed with comments, additions and ideas (on the content, appearance and style of the documents).

The researchers and co-researchers developed a list of institutions (schools, organisations providing services to transnational families) and individuals, adults and adolescents in Romania or Moldova and disseminated the final version of the invitation to them. A number of four co-researchers reached out to fellow children inviting them to interviews.

Data Collection

The data collection phase involved individual interviews, family interviews and focus groups with respondents who included children and adolescents, parents and caregivers, respectively, along with the representatives of different institutions and organisations with a role in supporting transnational families in the three countries. We offered the adolescent co-researchers other possibilities of involvement. After a new training module (interviewing skills), they could choose to attend the interviews led by an adult researcher and intervene if they considered it useful or to conduct interviews individually or in pairs (in the case of family interviews or focus groups) with supervision (having a discussion before and after the interview with an adult researcher). No one from the co-researcher team opted for any of these activities, either attending the interviews or conducting interviews individually or in pairs.

Analysis and Interpretation

At the time of preparing this chapter, data from children were being interpreted by seven of the co-researcher team. They received the primary processed results of 26 individual child interviews and five focus groups with 29 children (the co-researchers did not want to participate in the coding of the interviews and analysis of the results). In the interpretation session with the co-researchers, we aimed to identify and reflect on the key outcomes that the co-researchers considered to be most important in supporting transnational families, based on the data provided by the children. In the following, we present a few key issues highlighted by the co-researchers related to the parent–child relationship and the impact of parental migration on adolescents.

Co-researcher adolescents were much involved at this stage, participating in the data analysis and giving their interpretations based on their experiences. From their perspective, the relationship of trust between parents and children is influenced by the extent to which the child was involved in family decisions from an early age.

> If one hasn't been involved since one's a child, when one gets older, something from the trusting relationship is lost. (N, 17 years old, girl)

Other co-researchers noted the importance of maintaining family bonds, the child–parent or child–caregiver communication (facilitated by modern tools), higher-quality relationships and cohabitation among nuclear transnational family members as factors with a high positive impact on children's well-being, as previously described in other studies (Ducu, 2014; Mordeno et al., 2022; Nedelcu & Wyss, 2016). Ensuring family members stay connected – having meaningful and not only superficial conversations, being available to each other, and having regular, frequent contact – often requires considerable effort.

> You have to know what time you can call, if it's at work to be on break … to be alone, to be able to speak. (I, 16 years old, girl)

Participants identified the need for privacy when communicating with parents, both for them and their parent.

> Most of the time, parents who are away for work do not live alone, they live with several people. They can't communicate freely either. (O, 17 years old, girl)

If parents or children lack this opportunity or don't invest in staying connected for a long time, they may lose touch and establish a separate or parallel life.

> Now, I honestly don't care when he [her father] comes and goes. I'm used to it, and it's normal for me. (N, 16 years old, girl)

A challenge for the emotional well-being of LBC is that most often, migrant parents invoke children's needs when explaining to them the decision to migrate and consequently, a sense of culpability may develop in children (Cheianu et al., 2011; Pantea, 2011). Money is a sensitive issue that can often cause tensions in parent–child relationships. The co-researchers also reported that most parents believe that financial support is critical, whereas for children, the parent–child relationship is more important.

> Every time a conflict arises, my parents reproach me that they work hard for me, that I have everything [I need] and I am dissatisfied. I tell them that I want to talk about more than just money. Or when I'm angry they ask me, "What happened to you? Do you want us to send you some money?" (U, 15 years old, girl)

According to co-researchers, it is necessary to emphasise that during the time of parental separation, children gain more autonomy and become more open and knowledgeable in the world: 'We know more than one country, more cultures, more habits, eating habits, dressing habits, different ways of thinking' (O, 17 years old, girl). They make decisions independently, manage the money sent by their parents and run the household. These findings were also observed in other studies, like Deng et al. (2022) and Pantea (2011). At the same time, co-researchers considered it particularly important to establish safety for the left behind family, mentioning special measures in cases where children are eventually left alone and the caretaker person has some specific needs (health problems, an advanced age, etc.). In this case, in their opinion, intervention by the authorities is necessary. In addition, co-researchers showed that they were also aware of the benefits of parents working abroad and emphasised that there are situations, like parental violence, when the migration of parents is clearly beneficial for the child if the abusive parent moves abroad. One of them disclosed being a victim of violence:

> As it is in my case, . . . it's hard because I feel very lonely. [. . .]. But it's better this way, with my dad away. Now at least he can't beat me. . . . It's good, it's better this way. (C, 16 years old, boy)

The tendency to set high standards for LBC was also identified. Co-researchers described the academic success of LBC as a form of reward for the parents' efforts – a similar explanation was provided by Botezat and Pfeiffer (2020) and Démurger (2015).

> I always felt obliged to study well, as an appreciation for the work of my parents. Even if it can go into extreme perfectionism, it is a kind of obligation towards the parents. They go to work because they have to, and we learn because we have to. (I, 16 years old, girl)

Dissemination

Because the research data are not yet fully processed, dissemination is still in its early stages. The initial ideas put forward in the proposal are constantly being reconsidered by the team. The co-researchers will be involved in contacting and talking to the target audience and developing the contents of the dissemination materials (presentation of research findings at conferences, proposals for professionals in the child protection system, training materials, proposals for the development of child and transnational family support policies).

The main role of the co-researchers is developing information materials (online brochures and videos) for children, parents and caregivers in transnational families.

Related to future training for parents and specialists who work with transnational families, the co-researchers suggested that a 'school for parents' would be useful, in which they would be trained in facilitating communication with LBC, particularly how they can stay in contact, develop a partnership with children and adolescents (changing parents' beliefs that children should 'just listen and obey their parents') and provide appropriate discipline (to prevent abusive behaviour).

They all agreed that social policies to protect the best interests of the child should include measures to prevent parents from working abroad (adequate financial support) due to subsistence poverty or unemployment.

Because the project team foresees activities focussed on decision-makers and professionals providing support to families, to the current project phase, two of the co-researchers have contributed to elaborating draft recommendations on supporting transnational families and LBC in need that they consider important from the children's point of view.

Effects of Research Experience on Co-researchers

Adolescents stated that participation has been empowering in several respects. They felt valuable and proud as co-researchers. Aligning with the experiences of other co-researchers (Damsma Bakker et al., 2021), the co-researchers in this study highlighted that making a positive contribution to the lives of others is one of the greatest benefits.

> It's a good feeling to help others. I came because I would like to help. … I would like it to be easier for other children whose parents are away. (C, 16 years old, boy)
>
> It is a unique opportunity to do something as a child to make things better for other families. (T, 17 years old, girl)

Though they did not feel that they developed special research skills, they enjoyed each other's company, being able to think together and sharing different life events that they don't usually discuss with other teenagers.

It is important to mention that one of the most important effects of the collaboration on researchers, as other scholars have found (Sandwick et al., 2018; Van Staa et al., 2010), was the fact that children's involvement prompted us to maintain a certain level of sensitivity to their experiences and fidelity in transmitting their perspectives, without which true listening, would not be achieved (Lundy, 2007; Lundy et al., 2011).

During each meeting, the young people pointed out the importance of reflecting on why parents needed to go abroad for work. When discussing social policy ideas, they insisted on the responsibility of the community and authorities to analyse, monitor and develop strategies to manage the reasons why parents leave. However, they were aware of the difficulty of changing the community, the fact that migration was the given basis for the project, and that prevention of migration is complex. Thus, the researchers adopted the insights offered by the co-researchers' group, keeping their messages as accurate as possible. Despite some criticism expressed by experts working with transnational families to whom we presented our results elaborated with adolescent co-researchers, we will not abandon our child-adapted participatory methods (Coyne & Carter, 2018) and following Lundy et al. (2011), we do not consider children's analysis to be childish. Facing such criticism gave us the chance to reflect on the advocacy role of researchers involved in participatory action research – to empower children, researchers also need to prepare the adult community to accept and value the perspective of children instead of refusing these opinions as childish or naive.

Another example relates to young people's opinion on parental involvement in activities that improve communication between parents and children. The teenage co-researchers have proven to be very reserved regarding the training courses offered to parents. On one hand, they expressed their distrust regarding the desire and ability of parents to change their attitudes towards children. Instead, they proposed training courses for the next generation of parents – today's teenagers.

Co-researcher teenagers also gave voice to their solidarity with parents and revealed their wishes to protecting them, saying that 'they [parents] have enough weight on their shoulders' (O, 17 years old, girl) and 'they have to deal with adjusting there [abroad], not with us' (T, 17 years old, girl). Such discussions about adolescents' willingness to protect parents and sharing responsibilities with them for the sake of improving the economic situation of the family raised new and important topics for future interviews, counselling and training guides on parental abilities.

Concluding Dilemmas and Challenges

The topic of parent migration and its effects on the family environment has become a focus of moral dilemmas for a decade. In this vein, children have been portrayed as social orphans and parents working abroad as neglectful parents. Today, with more evidence from research with adolescent co-researchers, the impact of parental migration on children has become more comprehensive and nuanced, demonstrating that young researchers have the capacity to recognise the direct effects of the pressures imposed on them on their state of mind, but also on their peers, including both noxious effects and empowering effects.

The biggest challenge thus far has been to maintain interest and mobilise young co-researchers throughout the process. Despite the efforts of the research team, the co-researchers were not interested in getting involved in the data collection phase (conducting interviews or assisting in interviews conducted by researchers). It seems that they did not feel prepared to join the interviewing process, either in individual interviews with children or adults or in family interviews and focus groups.

We are left with the question of whether we took all necessary measures for mobilisation and information; could we have done more or done things differently? Co-researchers might need more training before joining an interview, or they might simply not have been interested at this phase of their lives in becoming researchers, but more in making their voices heard. Another hypothesis is that they were used to working as a group of co-researchers, so maybe their participation in data collection could also occur in smaller groups. Further activities with the group of co-researchers will bring more clarity.

An even more important question is whether in such situations, we should put more pressure on co-researchers' participation or accept their decision not to participate as an indicator of democratic collaboration. According to the adopted research ethics for voluntary participation, we have chosen the second option. According to our credo, the team of researchers must adapt to the needs of the co-researchers, not the other way around (Kiili & Moilanen, 2019).

Another important challenge arose from the characteristics of grant-based projects – namely, managing the constraints of the obligations assumed in the project, such as the timeline of activities or the budget, which limited the flexibility necessary to work together with adolescent co-researchers. Participatory research is a living, emergent, flexible process in which the dynamics of interaction with young people can turn to new directions in research or interventions (Kiili & Moilanen, 2019; Reason & Bradbury, 2008; Siry, 2015).

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Chapter 11

Change the Mood! Participatory Action Research With Children Affected by Community Deprivation

Natália Fernandes and Maria João Pereira

Abstract

The neighbourhoods surrounding social housing are often characterised by poverty, high rates of unemployment, community violence and other social stress factors that are often linked with adverse childhood experiences, including diverse forms of family, community and institutional violence against children. Based on the sociology of childhood, which considers children as active subjects with rights and promotes a critical understanding of their participation in matters that concern them, this chapter reviews participatory research with children, highlighting the importance of hearing their voices, to sustain their key role in building knowledge about them and the contexts in which they live. In this case, children participated in research to provide a deeper understanding of their needs in their neighbourhood, the role of their families and communities and what they needed to improve the quality of their lives.

Keywords: Children's participation; participatory action research; deprived community; disadvantaged children; social exclusion; stigma

Introduction

Being a child can have different meanings that bring different ways of being in time and space, and the place a child occupies today 'in everyday life is not the same nor is it, surely, still, in all places and at the same time' (Trevisan, 2007, p. 2).

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According to Marchi (2007), the 'awareness of childhood diversity' refers to the existence of social inequalities among children around the world. It is a reality that we cannot ignore, and it makes a difference in childhood, because it can result in the unfolding of many childhoods.

Children who live in social housing neighbourhoods (publicly subsidised housing) are the same as many others, but also very different due to the spatial and social contexts in which they are placed, which influence their ways of being and acting and their well-being and rights. Social housing neighbourhoods are often marked by isolation, stigma, exclusion and even self-exclusion. Some children are exposed to dangerous situations, such as parental neglect or domestic violence. They often have school careers marked by failure, fuelled by the parents' lack of interest in school and consequently, in their children's education.

Generating knowledge on the lives of children, from their points of view, has been the major contribution of childhood studies since the 1980s, in general and among children who live in deprived contexts, based on the assumption that children are active social actors with relevant voices and social behaviours. Linked with this epistemological issue, several methodological frameworks have since been developed with respect to this epistemological and political stance.

Participatory Research With Children in Deprived Neighbourhoods: A Tool Against Social Exclusion?

Participatory research with children has been identified as a research method that allows us to respect children as competent subjects who can observe, act, describe, explain and interpret the social reality that is significant to them. This research method makes it possible to view children beyond the classic negativity that characterises methodological approaches because it explores and highlights their skills, rather than focusing on their limitations and incompetence (Fernandes, 2016). Thus, we consider participatory research not only as a powerful tool for knowledge production with children but also as important to develop children's lived citizenship, which has strong implications in the traditional roles of children and adults, implying a transformation in the unequal power relations between adults and children.

Participatory research with children emerges as a criticism of positivist and functionalist models, which defend neutral, apolitical and uncompromising conceptions of science, and assumes that children's participation is a fundamental tool to fight against cycles of exclusion (Soares, 2006).

Lincoln and Guba (2000) identified the participatory paradigm, which came from the critical social sciences and is viewed as a political movement and multifaceted process of investigation, education and action. These issues were already pointed out by Freire (1973), who described the need to consider reflexive and critical dialogue in a horizontal relationship between the researcher and participant. By mobilising children's active participation in research processes, we also create an opportunity to promote children's status as active holders of rights in the multiple dimensions of provision, protection and participation. We also sustain that methodological approaches of research with than rather on children demand a strong ethical relationship in which power relations are deconstructed so children can go beyond being participants and become researchers.

As stated by Lundy et al. (2011), considering children as active holders of rights via explicit strategies that allow them opportunities to express their points of view, to become critical and active subjects in their lives, is a basic step to promote authorship of own protection (Fernandes, 2016). Bergold and Thomas (2012) also pointed that participatory research is important 'to involve marginalized groups in the production of knowledge and thus stimulate empowerment. The main objective of participatory research is to give a voice to members of marginalized groups or to enable their voices are heard' (pp. 201–202). Still, Cuevas-Parra and Tisdall (2019) argued that participatory research is a tool that provides opportunities to engage children and young people in shaping policy and practice and thereby, to shape their lives.

When presenting collaborative studies with children and young people in several contexts in Ghana, Malawi, South Africa and Tanzania, Porter (2016) discussed the need to have a strong ethical approach that is applied from the stage of planning throughout the research process to ensure a sustained commitment among all involved in co-investigation projects. The author also made the point that participatory research approaches with children and young people 'dont offer rapid or certain success and are unlikely to make much of a dent in the massive power imbalances within which global relations are embedded, even when stringent efforts are made towards inclusiveness' (p. 300). Nonetheless, they still have strong implications not only for individual peer researchers but also their wider communities.

In a study involving 711 children aged 10–17 years referred to primary care services in a socioeconomically disadvantaged neighbourhood in the suburbs of Rome, Italy, Ralli and colleagues (2020) provided an overview of several key elements to better understand children's lives in these contexts. They identified the availability of health services and access to basic housing and hygienic facilities as major issues.

In sum, participatory research with children is especially relevant to developing research processes with children who are at risk and vulnerable, because it is an excellent tool to deal with risky and dangerous situations, given the dynamic process of reflection and action in which children get involved (Fernandes, 2016).

Evidence arising from the development of participatory research with children who are at risk of or in vulnerable social conditions indicates that it enables them to develop skills to become more critical and agentic about their lives and have opportunities to search for protection (Santana & Fernandes, 2011, p. 13).

The Context of Participatory Research

The neighbourhood under study in this research – Lagarteiro, in Porto, Portugal – was the target of a Portuguese strategy based on economic cost containment, namely, 'the lowest cost attributed to each home and the high density required' (Ribeiro, 1979, p. 31).

As Park (1992) pointed out, the poorest people were automatically excluded from certain areas of the town, due to the price of housing per square metre, which they cannot afford, the result being 'tenements that are inhabited by large numbers of poor class people, unable to defend themselves from mingling with marginals and addicts' (p. 63).

Lagarteiro is considered a problematic neighbourhood in Porto, a label that is linked with the location in the periphery, disintegrated from the urban network. The major issues identified and associated with this neighbourhood are crime and deviant risk behaviours (drug trafficking, theft, robbery, bodily harm); negligence and abuse; family breakdown; unemployment and inactivity; dropout or school failure and low qualifications; a culture of subsidy mentality; human trafficking; marriages of convenience; and domestic violence (higher incidence than other neighbourhoods), among others.

Some children are exposed to dangerous situations, such as parental neglect or domestic violence. Their school career is often marked by failure, fuelled by their parents' indifference to school and consequently, their children's education.

Most children who participated in the present study came from socially disadvantaged conditions and sometimes persisting situations of poverty, exclusion and social precariousness, forming a downward spiral of social problems.

When neglected, some children adopt role models who engage in risky behaviours or deviant practices. The strong influence of these peers has consequences regarding absenteeism and early school dropout, with several children failing school.

Being born and growing up in social housing neighbourhoods, such as Lagarteiro, does not guarantee a life marked by precarity and personal and professional failure, but it contributes to this likelihood. As Pinto (2007) pointed out, there is a tendency for individuals to live according to the lifestyle of the household to which they belong: 'Unfortunately it is also possible to see that in Lagarteiro the social reproduction that leaves the subsequent generation in the same structural and social position in which the previous generation was is mostly the rule' (p. 142).

For most of the children who participated in this study, their neighbourhood streets often represent a second home, because in their household they do not always find a good family environment or the right conditions that can make them feel comfortable.

The neighbourhood is where they have their home and their family, but also where they play and make friends. The children enjoy the outdoor space more and have greater freedom for street games, which provides important playing spaces (Tranter & Doyle, 1996). In economically disadvantaged contexts, street spaces emerge as an important focus of leisure and interaction, as places of choice and other equipments that does not exist in the neighbourhood (Matthews, 2001).

Also, it is important to consider that territorial stigma is frequent and refers to a self-exclusion that isolates, affecting both adults and children, showing, often, a taste and distaste for the neighbourhood (Pinto, 1994).

Data from the Commission for the Protection of Children and Youth show that several children from the neighbourhood were referred to child protective services (Trigó, 2015), often making it difficult for them to continue living in these places. According to the Commission for the Protection of Children and Youth of East Porto, in 2015, the Lagarteiro neighbourhood had 48 cases. It should be noted that at the time of this research, of the group of 38 children involved in the present study, six had protection processes underway. The issues experienced by most of these children and their families, even those not flagged by the commission, often translate into domestic violence; consumption of alcohol or drugs by parents or guardians; drug trafficking in the nuclear family; arrest of one or both parents; low incomes; accumulated debts; subsidy dependence and single parenthood.

The Participatory Research Process

The participatory research ‘Children’s participation in territories of social exclusion: possibilities and constraints of children’s active citizenship’, from which we will be presenting some data, has as research goal the need to mobilise children as active agents in the process of giving meaning to their lives in the neighbourhood surrounding social housing which they lived.

Given the situation of the children in this housing area, the authors’ objective was to enrol these children in research process that enabling them to collect information and plan changes to improve the conditions of their lives. Through the research process, one major goal was to promote children’s critical thinking, reflection and participation regarding the issues that affected their well-being in the neighbourhood. This was as important as the different research tools and data collection process. We considered that all the steps children developed during the research process were very important contributions to raising awareness of the problems that affect them but also the possibilities to overcome these problems.

The research was developed during two years and had the participation of 38 children aged between nine and 12 years old, that attended primary school (Lagarteiro neighbourhood) and secondary school (Cerco neighbourhood). Most of the children came from deprived social conditions (poverty, exclusion and social precariousness). In this chapter, we will be talking about data only related with children from Lagarteiro neighbourhood.

The research process followed important ethical issues, namely the need to balance research risks and benefits, which demanded an ongoing critical commitment during the research with children, their well-being and rights; also the process of obtaining free and informed consent from children, parents and teachers was assured by informing them about their voluntary participation, the possibility to withdraw without any penalty, the possibility to access the findings of the research and the possibility to clarify their understandings.

During the research process, several research tools were used: 115 meetings with children, 30 interviews with children, 100 interviews with adult researchers, 165 drawings, 386 images and 165 field notes from researchers.

Through these data, the children identified and made known their ideas, identified some problems about the neighbourhood (violence and filth were the most common), offered proposals with a view to their resolution (Vis et al., 2011) and attributed responsibilities. From the identification and recognition of problems and responsibilities, the children organised planning actions and looked for solutions to their problems. They created several participatory tools through which they sought to intervene in their life contexts, as stated by Santana and Fernandes (2011, p. 14), when defending that data resulting from participatory research allow portraying 'more reliably the reality of children'.

The methodological framework based on a participatory research approach allowed the development of a shared relationship with children (Francischini & Fernandes, 2016) and knowledge production based on their representations and actions. The collected data allowed us to portray the reality of children in a well-grounded way (Santana & Fernandes, 2011). Under these assumptions, it was possible to plan for change with and for children in an active and dynamic way.

This participatory process resulted in initiatives fully considered by the children, who looked to adults for the support they needed and with whom they shared decisions with a view to implementing them (Hart, 1992; O'Kane, 2008; Shier, 2001).

During this process, children showed that they have the determination and skills to make their voices known, using information and dissemination tools to assume their roles as participatory and active agents. Several strategies were developed by the group of children to achieve their goals:

- The newspaper *Os Pequenos Jornalistas* (The Young Journalists), whose imprint resulted from the realization of a market where children sold used products.
- The documentary *O Bairro do Lagarteiro Pelas Mãos dos Pequenos Jornalistas* (The Lagarteiro Neighbourhood in the Hands of Young Journalists).
- An awareness session in the EB/JI (basic school) of Lagarteiro and the Teatro das Lições (Theatre of Lessons) with the aim of sensitising other students, families, teachers and staff for issues that were of concern to children. The stories were about education, hygiene, garbage and respect for others.
- The organisation of the group Missão Ajuda Júnior (Mission Junior Aid) with the aim of providing help to the most deprived residents of Lagarteiro.

Some of these tools had a larger scope, such as the newspaper and documentary, through which the children sought to overcome the invisible barriers of the neighbourhood, whereas others were more limited to the territory, such as the awareness session or Theatre of Lessons. In any case, the main objective of all strategies involved sensitising others (whether children and students or families, teachers and staff members) to various issues that concerned the children.

In addition to these tools, the children resorted to institutions that they considered able to operationalise their desired change, such as the Municipality of Porto and the EB/JI of Lagarteiro. Thus, they requested meetings with the coordinator of the school and sent a letter, via email, to the mayor of Porto. Meetings with the school coordinator were held whenever requested by the children, but the document sent to the municipality never received an answer.

All the collected data were returned to the children who generated them for analysis and modification if they felt the need, promoting their participatory role and legitimising them as co-researchers. We considered the return of data an important moment of the research because it allowed a collective validation of the elements collected and promoted discussion in a more structured and organised way.

The partnership developed between adults and children, in participatory methods, does not ignore the fact that children are social beings protected by adults, but this does not invalidate that partnership, because children can create their own interpretations, reinterpret others and bring authorship to the process. Moran-Ellis (2010) considered that participatory methodologies make it possible to reduce the impact of the presence of adults who guide the investigative process, especially their influence on children, whether direct or indirect, contributing to the development of a more balanced and horizontal relationship with the participants in the research.

Results of Acting for Change With Children

Children played an active and participatory role, making known their perspectives and meanings in relation to their ways of living, allowing us to get a better understanding and deeper knowledge of their worlds. They observed, reflected and verbalised their intentions, developing projects that materialised their aspirations for change. They sought to operationalise change in their social reality, mobilising tools of participation that resulted in ideas they put into practice.

This active and civic participation allowed the children to see change in their living contexts but also in themselves, others and the roles they all played (Graham & Fitzgerald, 2010). As active citizens, children participated and became involved in the society of which they were members (Ballesteros, 2016).

According to this group of young co-researchers in the community, the people (children and adults) who inhabit the neighbourhood are largely responsible for the numerous difficulties that haunt that place, preventing it, according to them, from being a better and different place.

They assumed a critical attitude that often generated discussions in the large group, caused by divergent opinions on a given subject. Criticism almost always arose but was accompanied by a constructive attitude to propose a solution for most of the problems presented. Although children were not always responsible for solving the problem, they always presented a proposal of what or who could help with the solution of a given issue. For example, the Municipality of Porto was often presented as the viable and transversal solution to the different problems they identified:

> I'd go to the city hall or anywhere, a place where they run the neighbourhoods. I would go there and say, "I want to change a lot of things," and if they would listen and if they wanted, they would start doing that. (Deborah, interview, 2014)

Participants identified the behaviour of people in the social housing neighbourhood as the origin of many of the problems they identified. The inappropriate behaviour attributed to the residents of the neighbourhood involved both children and adults, although with slight differences, particularly in attitudes. Children identified behaviours such as mistreating and abandoning animals; spoiling equipment, houses and nature; shouting and swearing; and finally, manifestations of violence, both physical and verbal, although they only associated domestic violence with adults: 'Sometimes even adults get into a fight' (Dinis & Tiago I, text excerpt, 2014).

In the behaviours attributed only to children, mischief stood out, which participants described as including throwing stones, making graffiti and disrespecting others. In the case of adults, specific behaviours included breaking in people's houses, problems with addictions (alcohol and drugs) and disrespect for traffic signs, particularly in parking lots, at crosswalks and with respect to traffic lights:

> If possible, we should force people to use crosswalks for their safety, so as not to be run over. Because if they were run over, their family would be very sad. (Dinis & Tiago I, excerpt, 2014)

Some children were very critical of behaviour in which they also engaged. Although they condemned and disproved these acts, being fully aware and verbalising what was considered right and wrong for them, sometimes when it came time to place trash in the garbage can, they did not do so. Then, they felt shame because they recognised that they had perpetrated the same behaviour that they criticised so much in other residents and neighbours.

In some cases, we could see that when they analysed their littering behaviour and became aware of the consequences of their act, there followed a change in already somewhat rooted behaviours and habits, as a discovery and a new learning.

From then on, placing trash in the garbage can became for them almost a point of honour. As the coordinator of the EB/JI of Lagarteiro explained, the change in attitude in children occurred alongside a strong desire to change the attitudes of others, even though sometimes they felt somewhat frustrated for not being able to achieve the desired effect:

> They came to me many times … "Oh, teacher, look at the playground! We've told them so many times to pick up their trash and they don't do it!" (Silva, interview, 2015).

By becoming co-researchers, examining their communities, reflecting on what happens around them and discussing in their groups what they like or do not like, children gained an awareness of their ability to choose what they want for themselves and what path they want to take. In some cases, it seemed as if the kids were looking at the neighbourhood for the first time, because until then, it was like they had never really seen it. Graham and Fitzgerald (2010) reported that the involvement and participation of children in research, in addition to providing an opportunity for discovery and negotiation, sometimes transforms the conceptions they hold about themselves and the role they play in society. From the moment this consciousness is aroused, children experience freedom of choice. They can choose to be like those whom they recriminate, acting by imitation and appropriating the behaviours they see in adults, through which they 'share the social world, build a common universe of meanings' (Gouvêa, 2011, p. 556). On the other hand, they may choose to differentiate themselves and counteract those behaviours, acting in opposition to them.

The children proposed many solutions, although they all had in common the same goal of alerting people of the neighbourhood to be aware of the problem and the need to change their behaviours.

The children were unanimous about their efforts to realise these small achievements, considering that because of their interventions in the neighbourhood and school, these places were changing, becoming more beautiful, cleaner and tidier. The residents, including the children, now had an example of how to behave, and this example showed them how they could change their attitude.

In view of this, children argued that in a certain way, others recognised them as responsible for the operationalisation of these changes:

> The kids and the people who live in the neighbourhood learned that we are kids who do not like to drop litter, that we like to do things right, and our schoolmates got to know that one should not spoil one's belongings. (Quaresma, interview, 2015)

Reflecting on their needs and acting to change was the motto adopted by these children, who revealed social skills of participation in their living contexts, in the sense of understanding and becoming acquainted with various social problems, for which they presented solutions. They revealed skills in identifying, planning and streamlining processes that have made them more autonomous and protagonists in their lives.

Along the way, the participatory process developed by the children faced constraints that limited the interventions they planned and at different times, proved to be obstacles to participation.

We consider that during the research process with children, the school had a relevant importance in the way these obstacles emerged. We developed our research with children that attended a primary school inside the neighbourhood. Due to this fact, the image and the role of these children as pupils was often superimposed in the activities, largely due to the interference of the adult teacher, who sometimes wanted his opinion and decisions to prevail over those of the children, but also due to difficulties that children faced because of all the other activities they had to develop as students. Marchi (2010) adds in this regard that this image of children as student's role brings a negative impact on their social action and participation because the institutional issues surrounding their place as students move children to the impossibility to give opinions neither to participate in the issues that are relevant for them.

On other hand, also, was very relevant to verify that these children needed the support of an adult, considering this support as essential to move on the processes in which they were involved. We noted what we call the (un)power of children, representative of the constraints of participation responsible for a decrease in the power of some children. This included tensions between children and adults (Ballesteros, 2016) namely the absence of power in favour of the adult.

When faced with difficulties, such as lack of collaboration, some children showed that they had a hard time including others in the participatory process, revealing an absence of collective awareness. From this perspective and to the extent that participation means being part of something, we can consider that children do not always internalise this concept inherent to the performance of full citizenship. Although many children noted that one of their most acquired skills during the process was teamwork, that goal was not always achieved.

Learning to participate (by participating) and making and establishing shared commitments (Cámara & Maria, 2012) were part of the process, but they were not always present, constituting barriers to participation.

Participation proved to be a privileged tool in the fight against social exclusion through the exercising of skills that enabled them to perform an active and inclusive citizenship (Santana & Fernandes, 2011). In the performance of their role as citizens, the children worked to meet their needs (Ballesteros, 2016), revealing levels of satisfaction, self-confidence and pride (Alderson & Morrow, 2011).

In this process, the adults were surprised by the participatory skills demonstrated by the children, especially those revealed in daily school life, pointing out changes in certain children's ways of doing and being:

> Their attitude has changed; their behaviour has changed. They were very quarrelsome at first. They continued to be, but much less. Maybe an ability to dialogue, to exchange ideas with others, in their own way. . . . I felt that, at the end, they had a more serious attitude. (Marques, interview, 2015)

In addition to the changes that some children operationalised in themselves, at the end of the present study, they made a point of highlighting the things they had learned (Willow, 2010). Learning to work in groups seems to have been the biggest change, given the number of children who identified this as one of the most important lessons: 'Children learn to work as part of a team, which strengthens solidarity, team spirit, and can help them to make new friendships' (Kränzl-Nagl & Zartler, 2010, p. 172), as evidenced by the following testimony:

> I realized it's not just – we have to – oh, I don't know how I'm going to explain! That we all have to work together and not just think about ourselves. We have to think of everyone. (Ana Rita, interview, 2015)

Although the participatory processes of children without adult intervention and participation could be considered more genuine, according to the opinion of the children who participated in the research, we consider that they were, in one way or another, affected or touched by the presence of adults, without whom children are rarely successful (Mannion, 2010).

Conclusions

As previously mentioned, the children took responsibility for the change they wanted to see in others, whether at school or in their neighbourhood. This was the result of questioning children about their lives in school and the neighbourhood. They chose to observe and reflect on their reality, so they could verbalise what they would (or would not) like to change and how they could achieve this goal.

Children initially identified the issues associated with their neighbourhood and school in individual interviews, at which time common denominators were identified and presented in a large group for discussion. In these moments, they explored the issues they raised through discussions, debates and brainstorming, among other methods. The children gathered as much information as possible on the subject and participated, making known their opinions and potential solutions for the items under analysis, then putting them into practice (Franklin & Sloper, 2005).

They voiced their opinions and perspectives through drawings, photographs, videos, interviews and focus groups that resulted in numerous data, allowing us to perform a rigorous analysis of the themes presented by them for discussion. Through these data, the children identified and made known their ideas – namely, how they envisioned change in their neighbourhood and school and their action plans to operationalise this transformation.

At various moments of our participatory research, the children revealed multiple skills in their analysis of, identification of and participation in the social living contexts, which they integrated, revealing an awareness of the social problems that affected them and for which they presented solutions. By performing their role as citizens, children added valuable knowledge to change their interactions in the deprived territories where they live, being able to envision, in these contexts, the changes they want (Santana & Fernandes, 2011) with increased insight but also a reflection on themselves, others and the roles they all play

(Graham & Fitzgerald, 2010). This would be the starting point for children who have begun to adjust the symbolic systems responsible for managing their social spaces (Sarmento, 2006) through behavioural change.

Their problems and behaviours led them to a self-analysis that resulted in their desire to modify their behaviours, which corresponded with those that they identified in others. The children felt the need to operationalise, in themselves, the changes that they envisioned for other people in their communities.

When reflecting on the operationalisation of their intentions for change, the children idealised and created several tools that they considered appropriate to the intended transformation.

At times, adults have contributed to limiting the participation skills of children, who have sought to find their rightful place, even though the adults often have the first and last word. The power of the adult, thus, frequently limits the exercise of active citizenship in childhood. The hierarchical relations of power are marked by the physical presence of the adult (Komulainen, 2007), but also the authority embedded in them (Delgado & Muller, 2005).

The children recognised the abilities of adults and sometimes compared them to their own, identifying adults as more capable and responsible, in contrast to the irresponsibility and folly of certain children. Liebel (2006) noted that the relationships between adults and children are often based on protection, sometimes clouding out children's voices and actions and blocking their participatory and decision-making skills. In this participatory research, these asymmetries were considered and explored, having been taken as a starting point for conscious reflection on the children's reality and a parallel effort to reduce these imbalances.

We tried to develop a close and dialogic relationship between the adults and children, keeping in mind the need to strengthen a trusting and respectful relationship to sustain a meaningful research process in which children could build a sense of belonging. In this relationship, the adult researcher assumed an open, receptive and facilitating posture and tried to interfere as little as possible. Also, the adult researcher sought to bring strategies that encouraged an active and dynamic participation, provoking reflection and questioning for decision-making. During this process, the researcher sought to reduce her role as a facilitator (Freire, 1973), trying to bring more children's participation to the project.

Throughout this process, power issues were very relevant for the researcher. Being attentive to the way the researchers approached and communicated with children – including care with our body posture, tone of voice and speech content, among many other elements – helped to ensure (or not) dialogic and shared relationships between adults and children.

By using questions, reflections and dialogues, we tried to build, as much as possible, the research instruments in partnership with the children, always considering their opinions and participation in the decision-making process (Hart, 1992; O'Kane, 2008; Shier, 2001), as reflected the following field note, in which we discussed the possibility of children being enrolled in the organisation of a newspaper. In a short time, the group of children developed concrete proposals that allowed them to move forward with the project:

> This is a newspaper that we made, as I said earlier, that we made a lot of effort to make. The newspaper about the neighbourhood and the school. (Tiago I, Field Note, 2014)

From their involvement in the organisation of such activities and others, children who participated in this participatory research built other important competencies, linked with their sense of belonging to the community and their responsibility for others and themselves, as shown in the following field note:

> We are not only representing our class, but we are also representing the school and the parish because almost nobody knows this school … and this neighbourhood. We are representing the neighbourhood, the school, and our class. (Tiago I, Field Note, 2014)

Children were aware of the prejudice against the neighbourhood, and through the research process, they became more conscious about their place and role there, assuming the mission to build a different image of their neighbourhood by changing with their actions those issues that affected their well-being and safety. Although childhood is not equal at all times and places (Trevisan, 2007), citizenship skills developed by children, in participatory processes, enable them to develop active citizenship and provide them with the necessary tools to transform the society of which they are active members, creating a place that is more respectful of their rights.

Participation, along with the assumptions of participatory research, emerges as a privileged tool in the fight against social exclusion and intervention in contexts of social vulnerability because it exercises skills that enable the performance of an active and as such, inclusive citizenship in the society to which children belong (Santana & Fernandes, 2011).

To sum up, participatory methodologies are important tools to develop with children that live in deprived and complex territories or contexts. However, these are not only moments of research but also moments of awareness, of critical reflection about their lives, and moments to be able to promote with the children very relevant citizenship competencies to face the risks they must face in their life.

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Chapter 12

The Inclusion of Children in Public Enquiries on Violence, Health and Welfare: The Example of Sweden

Laura Korhonen, Linnéa Lindholm, Maria Lindersson and Ann-Charlotte Münger

Abstract

Swedish society has systematically worked to improve children's health and well-being since the early twentieth century and is considered a leading figure globally in battling violence against children. Awareness of violence against children and its detrimental effects on development and health is generally high in Sweden. Violence is also broadly recognised as a violation of human rights. A ban on corporal punishment was enacted in 1948 in social childcare institutions, in 1958 in schools, and in 1979 at home. The more recent landmark was the United Nations Convention on the Rights of the Child, established as law on 1 January 2020. In line with convention's Article 12, stating that a child has the right to express their views in all matters affecting them, more attention to child participation has been paid since 2020. This chapter provides several recent examples of strategic measures that have been used to enhance child participation in governmental assignments and enquiries and state-funded research. We discuss the examples considering the United Nations convention and child participation methods and pinpoint opportunities and obstacles to further develop and consolidate child participation as a norm in publicly funded societal activities.

Keywords: Child participation; strategic measures; public enquiry; research funding; governmental guidelines; violence

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Introduction

Sweden generally has a high awareness of violence against children and its detrimental effects on development, health, academic performance and social relationships. Despite this, in the most recent national survey, 40% of school-age children reported that an adult had abused them in or outside the home (Jernbro et al., 2023). Similar results have been obtained in other recent studies, showing that one in four children has experienced sexual harassment and abuse during their lifetime (Svedin et al., 2021). The prevalence of violence against children seems high, considering the decades of work with child protection. It is, however, generally assumed only to be the tip of the iceberg, mainly because national prevalence studies on children younger than school age, disabled children and other vulnerable groups (e.g. refugees) are lacking.

Discourses on notions of children, their position and agency in society, violence against children and what is considered harmful to children have changed over time in Sweden. From the end of the nineteenth century, significant ideological, political, economic, social and cultural efforts have taken place while developing the Swedish welfare state. Violence is also broadly recognised as a violation of human rights, and society has, over time, invested substantial financial resources to ensure children's right to protection and support regarding exposure to violence (Littmarck, 2017; Sandin, 2018). During the 1990s, childhood sociological research also contributed with new perspectives on children and childhood. Accordingly, children are seen as competent actors in relation to the world around them (James & Prout, 2003). This perspective has been particularly important in the research field of men's violence against women, where the child's experience of violence has become an important part of understanding violence in the family (Edleson, 1999).

In Sweden, the ban on corporal punishment was enacted in 1948 in social childcare institutions, in 1958 in schools and in 1979 at home (Sandin, 2014). New legislation to criminalise witnessed violence in close relationships went into effect on 1 July 2021. In addition, the United Nations Convention on the Rights of the Child (CRC) (United Nations, 1989) was enacted as law on 1 January 2020. The incorporation of the CRC into Swedish legislation gathered the human rights concerning children in one act, making it clear that the CRC's articles must be interpreted alongside one another. It has highlighted that other laws, such as the provisions of the Children and Parents Code, the Aliens Act, the Education Act, the Act concerning Support and Service for Persons with Certain Functional Impairments and the Social Services Act in Sweden, must be interpreted based on the CRC.

Child participatory approaches in Sweden are often motivated by the CRC; thus, legislation can be considered one way to bring child participation into the mainstream (Fig. 12.1). Another strategic driver to strengthen child participation is clear governmental instructions to public-sector authorities. With these steering documents, child participation in the public sector can become mainstream. This

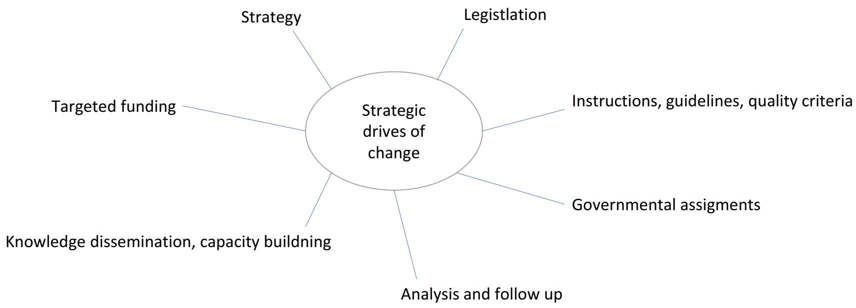

Fig. 12.1. Strategic Drivers to Foster Child Participation in Society.

can be augmented with guidelines and established quality criteria that make child participation a standard in public governance. One straightforward way to foster the child participatory approach is to include it explicitly in governmental assignments and general state enquiries. Several examples are given later in this chapter. Analytic work and follow-up of the child participatory approach in the public sector, including initiatives to combat violence and its negative consequences, are also ways to drive change in public governance, norms and values. This can be done via academic research or by giving specific governmental assignments. Data from these studies can subsequently be used to motivate further actions needed to mainstream child participation.

Information about the CRC and knowledge of child participatory approaches among professionals and those responsible for child services is a fundamental driver of change. Capacity building can be done by different means, such as providing theoretical training and practical tools to support professionals. In many cases, a pilot project is an excellent way to test how to increase competence. Knowledge about a child's rights and participatory approaches can be included in all relevant university education curricula at different cycles. Sufficient resource allocation and targeted funding can support capacity-building activities to foster change, especially during the early steps of mainstreaming.

Finally, national strategies are one instrument to mainstream child participation and implement children's rights-based approaches. Incorporating these issues in strategic and action plans enables work in different sectors and settings simultaneously for a more extended period. An action plan can include these strategic drivers, and follow-up of national strategies can consist of a separate analysis of the extent of child participatory approaches in public governance.

This chapter provides several examples of child participation in Swedish public agencies working on children's rights, violence against children, health and welfare. We discuss the examples considering the CRC and pinpoint opportunities to further develop and consolidate child inclusion as a norm in publicly funded societal activities. Also, we discuss observed obstacles and pitfalls.

Fostering Child Participation Among Public-Sector Authorities: Work Done by the Ombudsman for Children and Barnafrid as Examples

In Sweden, several government agencies work to combat violence against children by applying child participatory approaches. The Ombudsman for Children has the responsibility of promoting and advancing children's rights and interests in Sweden based on the CRC (Barnombudsmannen, 2021a). The Ombudsman for Children submits an annual report to the government, including recommendations for improvements, advocating for children and raising public awareness of children's rights. Children and young people are involved via interviews, focus groups, polls and meetings, and their voices are presented in different reports. The latest annual report, among others, recommended implementing systematic participation work in schools and municipalities (Barnombudsmannen, 2022). Input from children to this report was collected by interviewing 250 children and young people between the ages of 6 and 15 on possibilities to participate and influence decisions in schools. Also, a roundtable discussion was conducted with other relevant actors, including major national authorities and children's rights organisations. The Ombudsman for Children has also paved the way for child participation by involving children in several separate governmental assignments, as explained later.

The National Competence Centre Barnafrid was established in 2015 and is located at Linköping University, Sweden (Regeringskansliet, 2015). In collaboration with other relevant actors, the national centre is expected to identify needs for knowledge, collect and analyse existing expertise and research on violence against children and produce training and information materials. Furthermore, it should initiate or carry out joint interprofessional training and courses as much as possible in web-based form, create links between research and practice, facilitate increased coordination and promote networks for the exchange of knowledge between relevant principals, researchers, practitioners and organisations in civil society, both nationally and internationally. Finally, Barnafrid is expected to identify essential development areas and report these annually to the government. The instruction states that children's views and experiences must be made visible and considered in work appropriately, to the extent they are relevant. Differences in vulnerability between girls and boys should be noted.

Barnafrid has disseminated knowledge of the CRC and child participation, among others, via the digital Basprogram Barnafrid, which is a national reference education programme on violence against children (Barnafrid, 2020). The education is used in several first-cycle university programmes, especially those with a mandatory quality target on men's violence against women and violence in close relationships, including violence against children (Münger et al., 2021). Professionals also use the training individually and as a group in many workplaces covering different societal sectors.

As part of writing an annual report to the government on urgent matters in the violence against children field, Barnafrid (2022) involved children in the work.

Voices of young people were collected through a workshop with 14 high school students between the ages of 15 and 18. The participants had mixed nationalities, and the workshop was held in English to be inclusive. The workshop was conducted for a full day with two representatives from Barnafrid, who led the workshop and supported the students throughout the work. The child participatory workshop was organised using the Barnafrid child participation model, explained in detail in Chapter 7.

The young people discussed in various groups how violence appears in society today and the sort of violence to which children and young people have a higher risk of being exposed. Their thoughts about the risk of being exposed to violence as a young person developed into preventive measures, such as how to detect violence and what support from society may be needed following experiences of violence. The collected material was analysed with qualitative content analysis (Lundman & Hällgren Graneheim, 2008). The young people who participated in this workshop highlighted the need to draw attention to violence in, for example, school environments, domestic settings and online and to be aware of how differences in cultural background might increase the risk of exposure to violence. The group of adolescents also mentioned that it is significant to take notice of young people's feelings of not being listened to and taken seriously and that violence, in general, is not talked about in society to a sufficient extent. Therefore, more efforts are needed to prevent and detect violence to provide the proper support and help from a youth perspective. Personnel working in different leisure activities for children must dare to ask about violence. The adolescents emphasised a need for more well-developed systems to perceive children's exposure to violence. The following recommendations were made:

- Experts should ensure continuity of learning about children's exposure to violence for educators and social service officers when it comes to the negative consequences for children, normalisation processes and warning signs.
- Educational efforts should also be directed to children and young people to clarify what violence is and where to seek help exposed to violence.
- Parental education about violence and legislation (such as children's rights) is needed for parents with other cultural backgrounds.
- Continuous health check-ups should occur at school, where the topic of abuse should also be raised.
- Easily accessible support groups should be available for children and adolescents.
- Shorter queues and waiting lists should be ensured for victims of abuse seeking help from hospitals and psychiatrists.

The results were documented in a report that was included in the annual report to the government. Additionally, a video on children's voices was produced and presented to professionals attending a biannual national meeting on violence against children (Barnafridskonferensen) that Barnafrid organises. The workshop participants were actively involved in creating both the report and video. They also received feedback on these products after launching them.

Examples of Child Participation in Recent Public State Enquiries and Governmental Assignments Concerning Violence Against Children

Since 1 January 2020, when the CRC became a Swedish law, the government has initiated approximately 30 public state enquiries and governmental assignments relevant to violence against children. The projects span from protecting children from various types of violence (Government of Sweden, 2021d, 2021e) to proposing new legislation (Government of Sweden, 2020d), as well as national strategies to combat violence against children (Government of Sweden, 2021b) and improve equal health and health-care services for children (Government of Sweden, 2019).

About half of the initiatives clearly state the importance of paying attention to children's rights and perspectives. In most initiatives, instructions are given regarding what aspects should receive attention. These typically include gender equality, disability and minority perspectives apart from children's rights. Examples of formulations include:

> The child rights and youth perspective shall be taken into account.
> (Government of Sweden, 2019)

> In carrying out the assignment, NN shall pay particular attention to the rights arising from the UN Convention on the Rights of the Child (CRC).
> (Government of Sweden, 2021g)

> A starting point in the work will be the UN Convention on the Rights of the Child (CRC), which became Swedish law on 1 January 2020.
> (Government of Sweden, 2020d)

> The assignment will be from a child's rights, disability, and gender equality perspective.
> (Government of Sweden, 2021g)

> The Council of Europe Convention on preventing and combating violence against women and domestic violence, as well as the UN Convention on the Rights of the Child (CRC), will be the starting

> points for the mission. In the assignment, the special vulnerability of certain groups shall be considered, and the assignment shall therefore be carried out with an LGBTQI perspective and a disability perspective.
>
> (Government of Sweden, 2021c)

> When carrying out the assignment, (name of the governmental agency) shall consider the vulnerability and needs of persons with disabilities and LGBTQI persons. The representation of children and the rights of the child by the UN Convention on the Rights of the Child (CRC) shall be considered, and the recommendations on Sweden's compliance with the Convention on preventing and combating violence against women and domestic violence (Istanbul Convention) issued by the Council of Europe in 2019.
>
> (Government of Sweden, 2021f)

Other statements more explicitly indicate that child participation is expected, and sometimes they provide motivation. According to Shier's (2001) model, the level of child participation can vary from children being listened to (Level 1) or supported in expressing their views (Level 2) to be included in shared decision-making and child-led activities (Level 5). The following examples include lower and higher levels of child engagement:

> The assignment will be carried out from a child's rights, disability, and gender equality perspective. Children, parents, and guardians should be seen as important resources and allowed to participate in the development work.
>
> (Government of Sweden, 2020f)

> The agency will also seek the views of civil society organizations and other actors who have contact with children and young people and have knowledge about young people, sex and relationships, as well as violence in young people's relationships.
>
> (Government of Sweden, 2020a)

> . . . taken to children's opinions and experiences.
>
> (Government of Sweden, 2020e)

> The investigator shall also conduct a dialogue with children and young people to the extent deemed important.
>
> (Government of Sweden, 2022b)

> That the investigator, as far as possible, conducts dialogue and listens to children's opinions and takes part in their experiences is particularly important, given the assignment. Children with different conditions and experiences must be heard. Children's views and experiences must be considered in work.
>
> (Government of Sweden, 2022a)

> The investigator shall gather views from the relevant authorities, civil society organizations, and other relevant actors such as children and young people. The investigator shall start from the perspective of abused children, listen to children and young people, and consider their views and opinions in developing a strategy proposal. Children and young people have the right to participate and have their say in matters that concern them, and their opinions should be given importance. Children and young people possess expertise about the various bodies of society and the support that society offers, which is important for the investigator to take with them in the strategy design.
>
> (Government of Sweden, 2021a)

Most of these recent assignments and public state enquiries are ongoing; thus, we still need to determine the extent of child participatory approaches taken. However, a couple of projects have already been finalised. For example, a public state inquiry (Government of Sweden, 2021a) with an assignment to propose initiatives that will contribute to more equal care – including preventive and health-promoting efforts for children and young people and care for those with health-related needs such as mental illness due to exposure to violence – was instructed that 'the child rights and youth perspective shall be taken into account in the investigation, and the consequences for children and young people shall be particularly highlighted' (Government of Sweden, 2019). The enquiry's final report was published in 2021 (Government of Sweden, 2021a).

In this enquiry, several child participation methods were used in collaboration with one Swedish children's rights organisation and four high schools. The methods included a web survey for children aged 8–18 years, child participatory workshops, involvement of expert groups in schools and input from other pupils in these schools. Children discussed the topic of health and health services. In addition, another nongovernmental organisation was involved in the process. This organisation, Tilia (n.d.), has developed a method called *ungas röster* (young people's voices). In the framework of this method, decision-makers interact with young experts and facilitate their participation. The method is adaptable to different assignments, often with a basis in a preliminary investigation to create space for a more significant number of young people to have their say on an overall level, with subsequent in-depth interviews or questionnaires about young people's experiences. The work is then taken forward in workshops, in smaller groups with in-depth work and often on recurring occasions. The aim is for young people to be included from idea to finished decision or proposal. Using this method, young people had the possibility to raise their views, thoughts and experiences regarding health and the provision of health-care services. Also, in a public state inquiry, a web survey and qualitative interviews have been used to collect children's input to the work (Government of Sweden, 2021b).

Additionally, two governmental assignments to the Ombudsman of Children have employed a child participatory approach. In an assignment to gather knowledge about children's and young people's vulnerability to racism (Government of Sweden, 2020b), 73 children and young people aged 12–18 were interviewed to obtain their views (Barnombudsmannen, 2021c). Most children were aware of the rights of children to be treated equally while describing situations where they have been discriminated against because of their background, skin colour, gender, disability or simply because they are children. The discriminatory acts included different types of physical and mental violations and took place in different societal arenas. Several mentioned that racism is sometimes expressed in a joking way, which makes it more difficult to understand what is happening in the moment. The interviewees said they found it difficult to know how to act, set boundaries or speak up.

In another assignment to map knowledge about the impact of pornography on children (Government of Sweden, 2020a), the ombudsman met with 42 children and young people aged 15–26 to talk about their views on the topic (Barnombudsmannen, 2021b). Thirty-one participants were aged 15–18 years, eight were aged 19 or 20, and three were aged 21–26. Children and young people were recruited from different parts of Sweden and interviewed both in groups and individually to obtain information about children's and young people's thoughts and perspectives on the impact of pornography. The topics were focused on reasons to consume pornography and how society and decision-makers should act to best promote and protect children's rights when considering exposure to and consumption of pornography. The input from the children is represented as a separate section in the published report (Barnombudsmannen, 2021b). They emphasised the role of school sexual education in counteracting the negative effects of pornography.

Finally, the Swedish National Council for Crime Prevention was assigned to study measures against dating violence with instruction to explore children's and young people's views and experiences (Government of Sweden, 2020e). As part of this assignment, professionals from relevant agencies, civil society organisations and other actors in the field and young people subjected to dating violence were interviewed. Also, an idea workshop with young people was organised. Seventeen adolescents and young people aged 17–25 years were interviewed (Brå, 2021). The recruitment was designed to reach out to young people from different groups, both girls and boys; lesbian, gay, bisexual, transgender, queer and intersex people; people with disabilities; those newly arrived in Sweden; and young people who experienced honour-related violence. Recruitment occurred through a film ad and a poster disseminated via nongovernmental organisations and social media, among others. Upon contact with the project group, young people received more information about the study, ethical guidelines and consent. Semistructured in-depth interviews were conducted over the phone, followed by subsequent thematic analysis.

The idea workshop with young people was carried out by the youth organisation Youth 2030 Movement, which also recruited the participants. There was no requirement for experiences of being subjected to dating violence to participate. The idea workshop offered a method to empower and affirm young people, then collect their thoughts and opinions and share them with those in power, authorities and decision-makers. The idea workshop was conducted digitally with five participants aged 21–24. People of different genders and those who experienced same-sex and opposite-sex relationships were included. The participants of the idea workshop discussed and reflected on issues concerning knowledge and information about violence in young people's relationships and limits on legal and illegal behaviours. The workshop resulted in a problem analysis tree with causes, problems and consequences, as well as a solution list of what different societal actors and adults should do to counteract this type of violence.

We also found a few finalised assignments that were instructed to include child participatory activities but had not done so.

Requirement for Child Participation in Public Research Funding

Yet another recent example of how child participation can be fostered is a research call on children's and young people's mental health that the Swedish Research Council for Health, Working Life and Welfare (Forte) announced in spring 2022 (Forte, 2022a). The government's research and innovation bill 2020 (Government of Sweden, 2020c) commissioned Forte to establish a 10-year national research programme in the mental health field (Forte, 2022b). The spring 2022 call is the first one in the programme and the first with an explicit requirement for a participatory research approach. The call states:

> The funded research must be based on a child and youth perspective and a gender equality perspective. The research should consider Sweden's human rights commitments, the UN Convention on the Rights of the Child, the implementation of Agenda 2030, and Sweden's public health policy goals. The call is intended to contribute to increased knowledge about children's and young people's mental health, and applications within this call should focus on one or more of the areas described below.

In line with this, research being funded in this call must be planned and conducted in collaboration with relevant target groups such as users and clients, professionals or interest organisations when appropriate. It also states that participation should be promoted in different parts of the research process, such as the design of the study, data collection, analysis, dissemination of results and implementation. Increased quality and relevance of the research project are used to highlight the need for a participatory approach. To meet the requirements, applicants are asked to demonstrate that the research question is a priority for the target groups, the outcomes are essential for users and practitioners and clients and users will be involved in the research process. In addition, the research budget should include reasonable costs for participatory activities. One representative from children's rights organisations is included in the grant application evaluation group.

We still need more information about how child participation is considered in these applications. This and the obtained results will be reviewed during and after the research programme.

Child Patient Participation in Health Care and Clinical Research

Since 2015 in Swedish health care, clinics can apply for status as a university health-care unit if they fulfil the minimum criteria set by the National Board of Health and Welfare. The university health-care unit's core activities shall, in addition to health care, be clinical research and education, knowledge application and dissemination of knowledge for the development of health care (ALF-styrgrupp, 2015). In line with this, units with status as a university hospital clinic should conduct research and education; follow international developments in medical research, education and health care; contribute to evidence-based health care, for example, by evaluating and establishing new methods; and disseminate information and collaborate with societal actors such as patient organisations. A well-functioning health-care system is crucial in caring for children exposed to violence. Children should be allowed to participate in developing services related to the consequences of violence.

Two assessment criteria for patient participation are used (Socialstyrelsen, 2018) to evaluate the current status. One states that the university health-care unit 'uses data from measurements of patients' experiences and can report that this has contributed to the development of the clinical work', which refers to patients' experiences of their illness and health after treatment or other intervention (e.g. symptoms, functional ability, health-related quality of life) and variables related to treatment, trust, participation, waiting times, contacts and coordination. The other criterion states that the unit 'collaborates with patients and related or patient and related organizations in the evaluation and development work'. Both child and adult participation are considered.

All units with university health-care status were evaluated in 2018 (Socialstyrelsen, 2018), and a new evaluation is ongoing. Because the assessment results are coupled with the amount of research funding allocated to different hospital districts, interest in performing well has been noticeable. This has also incited efforts to improve participatory approaches at the unit, hospital and district levels. For example, the Östergötland region in southeast Sweden has established a board of patients, carers and relatives to encourage involvement of patients, including child patients at different ages, in the research and development taking place in the hospital units (Östergötland, 2021). For example, researchers applying for intern research funding are now required to explain how patients, relatives and patient organisations will be involved in the planned research project. Results from the ongoing assessment will be published in 2023.

Discussion

In summary, we have provided several examples of how legislation, governmental instructions, assignments, targeted funding, quality criteria and external evaluations assessing these criteria can bring child participation into the mainstream in the public sector. In this work, national strategies can provide a good framework.

In the Swedish examples, the ambition of child participation is set relatively low, corresponding to Levels 1 to 3 in Shier's (2001) model. Generally, the documentation in the published final reports is not very detailed, making it hard to assess how much children de facto are involved in decision-making processes (Levels 4 and 5). This is, however, entirely in line with the results obtained in two recent scoping articles on child participation (Grace et al., 2019; Larsson et al., 2018). Coming assignments should focus more on defining the expected extent of child participation in the future. Also, a closer follow-up of adherence to the instructions would further foster the implementation of the child participatory approach in governmental assignments and public state enquiries.

Several methods are described for child participation (see Chapters 2, 6, 8, 9, 10, 11). The Swedish examples used focus group interviews, in-depth individual interviews, web surveys and workshops and followed the methods identified in the scoping reviews (Grace et al., 2019; Larsson et al., 2018). Child panels were also involved in some cases (e.g. Government of Sweden, 2021a). The competence in child participatory approaches in governmental organisations seems to be limited based on using children's rights organisations to recruit child participants and provide methods for child participation (Government of Sweden, 2020e). In most cases, the methodology was generally insufficiently reported and mainly limited to content analysis and descriptive statistics. Also, the generalisability of the data has been seldom discussed. Considering these shortcomings, closer collaboration with governmental organisations and researchers would benefit the projects by ensuring their quality. This is critical because the data obtained in the governmental assignments do not undergo any independent peer-review process but are widely used to motivate different political and other decisions.

Only the Swedish National Council for Crime Prevention discussed ethical principles and consent in its report (Government of Sweden, 2020e). Swedish law requires ethical permission for research, including development activities that use research methods and collect sensitive information such as age, gender, health, committed crimes, etc. There is a grey zone regarding whether ethical permission should be applied for all or only some types of child participatory approaches. Adherence to ethical guidelines could ensure fair recruitment, collection of informed consent to participate and publish, data management security and other principles that ethical approvals typically consider.

We also noticed that some governmental assignments had been instructed to involve children but failed to do so. The reasons for this remain to be elucidated because they are not explained in the published reports. Following up on the situation and learning more about these cases is essential. The reasons may involve limited time and resources, lack of experience in child participatory approaches or as revealed by other studies, little acknowledgment of the benefits of including children, their guardians and other stakeholders (Hill, 2006). User-friendly methods for child participatory workshops and process-supporting materials are essential to mainstreaming child participation. Also, training should be provided to professionals and decision-makers in all sectors. This should include, at minimum, a rights-based justification for child participation, training in methods, documentation and child safeguarding.

Despite the identified shortcomings, a giant leap has been taken in Swedish society to ensure children can participate in publicly funded activities such as public state enquiries, governmental assignments and research projects. The impact of the involvement remains to be analysed, and the focus now is more on providing excellent and feasible examples of how to involve children. The recommendation made by the Ombudsman for Children to mainstream child participation in schools (Barnombudsmannen, 2022) could help us teach coming generations of children and young people to understand the rights of children, methods for participatory activities and relevant ethical principles (United Nations, 2009).

Child participation is often motivated by quality-improving effects and efforts to address issues that are the most relevant for different target groups (Brett et al., 2014). The development of services based on the needs and desires of children is well in line with developments in the management field, where more attention is being paid to user experiences (Lemon & Verhoef, 2016; Verhoef et al., 2009). Knowledge of how to combine understanding of experiences and needs with strategic leadership obtained in the management field could be helpful to facilitate improvements in public sectors like health care and social services, too. This may need a firm policy for public governance that positions clients as the focus, such as recent efforts in Finland (Ministry of Finance, 2020).

Further development of practical models to involve children exposed to violence in service and policy development is warranted. In this work, it is essential to pay attention to the involvement of children of different ages and backgrounds and to develop methods allowing adjustments, such as those needed for children with disabilities or requiring alternative communication tools.

Apart from model development, knowledge and competence improvement activities should be initiated regarding child participatory approaches among staff members and managers. Also, students at all university levels should be trained to enhance child participation in the public sector.

Conclusions

According to the United Nations Convention on the Rights of the Child Article 12, a child has the right to express their views in all matters affecting them. This urges mainstreaming child participation in research and development projects, and policy-making in the field of violence against children. Access to user-friendly methods and training are essential components in the facilitation of mainstreaming.

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Chapter 13

Survivors of Child Maltreatment: A Historical Review of Global Health and Research

Pia Rockhold

Abstract

Based on an extensive literature review, this chapter outlines key developments in global health and research during the last century with focus on the emergence of violence and child maltreatment as international public health priorities. Violence has been known to humans for millennia, but only in the late 1990s was it recognised as a global public health issue. Every year, an estimated 1 billion children are exposed to trauma, loss, abuse and neglect. Child maltreatment takes a social and economic toll on countries. Research initiated in 1985 found child maltreatment to be associated with increased disease, disability and premature death in adult survivors. The global availability of data on child maltreatment is, however, sporadic with low validity and reliability. Few global experts have consulted and involved the survivors of child maltreatment, as the experts by experience, in their attempts to provide a more comprehensive picture of reality. Youth and adult survivors of child maltreatment are often traumatised by the experience, and it is important to use trauma-informed approaches to prevent re-traumatisation. Participatory and inclusive research on child maltreatment is only in its infancy. There is a need for more inclusive research, designed by survivors for survivors, hereby strengthening local capacity building and informing policymakers from the bottom up. This chapter reviews lessons learnt and provides recommendations for how to enhance the participation and inclusion of the experts by experience in research on child maltreatment.

Participatory Research on Child Maltreatment with Children and Adult Survivors, 215–228
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Keywords: Child maltreatment; adverse childhood experience; trauma; violence; participation in research; historical review

Introduction

Globally, more than 452 million children living in conflict-affected areas are exposed to trauma and loss, the impact of which range from resilience to disease, disability and death (Save the Children, 2021; Stoddard, 2014). Every day, even more children are exposed to violence by the very people responsible for their safety and upbringing: parents, family, care facilities, schools, the social system, siblings, peers and others. Violence is a major public health problem. Every year, an estimated 1 billion children from 2 to 14 years old are victims of violence (World Health Organization [WHO], 2020). Violence in the home, with an estimated prevalence of 22% (Stoltenborgh et al., 2013), is predominant among children from 2 to 14 years old, Youth often have multiple exposures in and outside the home (Hillis et al., 2016). The global prevalence of child sexual abuse (CSA) is estimated at 11.8% (Stoltenborgh et al., 2011). A meta-analysis in Nordic countries revealed a prevalence of CSA from 3%–23% for boys and 11%–36% for girls (Kloppen et al., 2016).

Traumatic childhood experiences are important societal problems with far-reaching health and socioeconomic consequences. Abuse, violence and neglect in early infancy and childhood (child maltreatment) enhance the risk of attachment disorders, substance abuse and mental health problems, such as anxiety, depression, suicidal behaviour, personality and attention deficit disorders, post-traumatic stress disorder (PTSD), psychosis and bipolar II (Black, 2011; Leeb et al., 2011; Norman et al., 2012). Child maltreatment is further associated with increased risk of cardiovascular, liver and chronic lung diseases; cancer; stroke; injuries and disabilities (Bellis et al., 2014; Chiang et al., 2018; Danese et al., 2009; Felitti et al., 1998).

The health and social consequences of violence take an economic toll on countries. The provision of treatment, mental health services, emergency care, criminal justice responses and safety places represents some direct costs associated with violence. A wide range of indirect costs also occurs. Survivors of violence are more likely to experience problems affecting quality of life and school and job performance. Other indirect costs include those related to lost productivity because of premature death; long-term disability; disruptions to daily life because of fears for personal safety and disincentives related to investment and tourism. In 2004, the estimated direct and indirect economic costs of violence were equivalent to 0.4% of gross domestic product in Thailand, 1.2% in Brazil and 4% in Jamaica (WHO, 2008). In the United States, the total lifetime economic burden resulting from new cases of fatal and nonfatal child maltreatment is approximately $124 billion annually (in 2010 dollars; Fang et al., 2012).

Violence has been associated with humanity for millennia, but only since the late 1990s has it truly been recognised as a global public health problem and research priority (WHO, 1996). Survivors of violence, including children, youth and adults exposed to child maltreatment, are experts by experience. So how do we better integrate these experts in our research on child maltreatment?

Global Research on Violence, Child Health, Abuse and Neglect

In 1962, C. H. Kempe recognised the importance of child abuse and neglect. He established an international working group, and in 1977, he founded the International Society for the Prevention of Child Abuse and Neglect (ISPCAN) 'to promote opportunities, facilities and organisations which will enable the children of all nations to develop physically, mentally and socially in a normal manner . . . and in particular, to promote the protection of every child, in every country against all forms of cruelty and exploitation' (Kempe et al., 1962).

Kempe was ahead of his time. Although violence had long been known to humanity, only during the 1980s did it move from being a criminal justice issue to a public health problem (Winett, 1998).

In 1996, the World Health Assembly declared violence a major public health issue and called for promotion of research in the area (WHO, 1996). In 2002, the *World Health Report on Violence and Health* described different types of violence including child abuse and neglect, the size of the problem, risks and preventive efforts (WHO, 2002).

In 2006, the *World Report on Violence against Children* provided a comprehensive global scenario of the problem: 'Throughout the study, children's voices were listened to, heard and respected' (Pinheiro, 2006, p. XIX).

In 2009, the United Nations appointed a special representative to conduct a global survey on violence against children, published in 2013 (Office of the Special Representative of the Secretary General on Violence against Children, 2013).

In 2014, the *Global Status Report on Violence Prevention* found most of the 133 countries included in the survey to lack data on violence. Only 41% of the countries had done national surveys (60% in Europe) and prevention programmes were only implemented in a third of the countries. Laws existed in 80% of the countries but were only enforced in 57% of them. Safe places were available in half the countries (WHO, 2014).

In 2015, a global report on the prevalence of violence against children emphasised the need for more reliable and comprehensive data (UNICEF, 2015).

In 2016, global actors developed 'INSPIRE: Seven Strategies for Ending Violence against Children' in support of the globally defined 2030 sustainable development goals to (1) End abuse, exploitation, trafficking and all forms of violence against and torture of children; (2) Eliminate 'violence against women, and girls; and reduce (3) all forms of violence and related death rates' (WHO, 2016). In 2020, the *Global Status Report on Preventing Violence against Children* found 80% of countries had a partial action plan in line with INSPIRE, but only 21% had quantitative baselines and target indicators to monitor the effect. Implementation of preventive strategies was low (WHO, 2020).

Early Research on Adult Survivors of Child Maltreatment

In 1985, Judith Herman and Bessel van Der Kolk observed that many patients diagnosed with borderline personality disorder (BPD) reported maltreatment in childhood. To uncover the possible relationship between trauma and BPD, they developed the Trauma Antecedents Questionnaire (see http://www.trauma-center.org) and obtained a trauma history from 55 outpatients. The questionnaire gently approached the issue of childhood relationships and trauma, considering that most traumatised persons feel shame about past trauma. The study found that 81% of patients with BPD reported severe histories of child abuse including sexual abuse or neglect, usually before the age of seven (Herman et al., 1989). These researchers approached the team revising the *Diagnostic and Statistical Manual of Mental Disorders* (DSM; third edition), proposing that people with severe childhood abuse or neglect be diagnosed as having complex PTSD. To gain more information and compare different groups of traumatised individuals, an additional study including 525 adult patients occurred at five sites across the United States. The three groups of focus were: (1) adults with histories of childhood abuse, (2) recent survivors of domestic violence and (3) survivors of natural disaster. Adults who had been abused as children had problems concentrating, complained of being on the edge and reported feelings of self-loathing. They had trouble with intimate relationships and memory and often engaged in self-destructive behaviours. These symptoms were relatively rare in adult disaster survivors. The DSM (fourth edition) PTSD workgroup suggested survivors of interpersonal trauma be diagnosed as having ‘complex PTSD’, but the diagnosis did not appear in the final version of the fourth edition of the DSM (van der Kolk, 2015). PTSD for children aged 6 years and younger was recognised in the fifth edition of the DSM, along with the somewhat broader ‘trauma and stressor-related disorders’ (Luxenburg et al., 2001). The 11th version of International Classifications of Diseases includes the diagnosis of complex PTSD (see https://icd.who.int).

Adverse Childhood Experiences Research

In 1985, Vincent Felitti observed that some of the people in a Kaiser Permanente clinic for extreme overweight rapidly regained the weight they lost. Interviews with 286 extremely obese persons attending the clinic showed that a large percentage had been exposed to child abuse (Felitti, 2019). Although the data were interesting, the study population was small and nonrepresentative of the general population. The Centers for Disease Control and Prevention (2022), therefore, suggested a larger study. It took three years to design the retrospective cohort Adverse Childhood Experiences (ACE) Study, implemented from 1995 to 1997 at Kaiser Permanente with support from the Centers for Disease Control and Prevention. The study aimed to determine the prevalence of ACEs in the general population and how ACE affect adults later in life. The data collection was done in two waves.

In total, 26,000 adults who received an annual comprehensive medical examination were asked to join. Baseline survey data on health behaviours, health status and exposure to ACEs were collected from 17,337 adults who agreed to participate. Most respondents were White (74.8%); 11.2% were Hispanic and 54% were female. Nearly 40% had attended college or beyond. The study mainly included financially secure, middle-aged people with good medical insurance.

The ACE questions, which referred to the respondents' first 18 years of life, included 10 categories: abuse (emotional, physical, sexual); household challenges (mother treated violently; household members with mental illness, substance abuse or sent to prison; or parents separated or divorced) and neglect (emotional or physical). The ACE score was used as a measure of cumulative exposure to traumatic stress during childhood, with 0 being no exposure and 10 being the highest exposure. Two-thirds had an ACE score of 1 or more.

In the first ACE study published in 1998, a questionnaire was mailed to 13,494 adults; 70.5% (9,508) responded. Logistic regression was used to adjust for demographic factors regarding the association between ACE score (0–7) and risk factors for the leading causes of disease, disability and death in adult life. More than half of the respondents reported at least one ACE, and one-fourth reported two or more ACEs. People with four or more ACEs, compared to those with none, had 4 to 12 times the risk of alcoholism, drug abuse, depression and suicide attempt. They also had two to four times higher odds of smoking, poor self-rated health, more than 50 sexual partners, and sexually transmitted diseases and 1.4 to 1.6 times higher odds of physical inactivity and severe obesity. The ACE score showed a graded relationship with the presence of ischaemic heart, liver and lung disease; cancer and skeletal fractures in adults. The ACE score was interrelated, and people with multiple ACEs were likely to have multiple health risk factors later in life (Felitti et al., 1998).

The original ACE study was the first of its kind to find a strong graded relationship between ACEs and multiple risk factors for several leading causes of disease, disability and death in adults. Follow-up studies and papers continue to appear, mostly from the United States and mainly confirming and expanding on the initial findings (Chapman et al., 2004, 2011; Hillis et al., 2001, 2004; Oral et al., 2016; Whitfield et al., 2005).

A 2009 analysis of the ACE data for 17,337 adults found that 1,539 had died by 31 December 2006. The crude death rate was 91.0 per 1,000; the age-adjusted rate was 54.7 per 1,000. People with six or more ACEs died nearly 20 years earlier than people without ACEs (Brown et al., 2009).

A 2013 ACE study including four adult male offender groups (N = 151; nonsexual child abuse, domestic violence, sexual abuse and stalking) reported nearly four times as many ACEs compared to a normative adult male sample. Perpetrators of sexual offences and child abuse were more likely to report CSA than other offender types (Reavis et al., 2013).

A 2014 ACE study found that 47 female sexual offenders, compared to women in the general population, had more than three times the odds of CSA, emotional neglect, verbal neglect and having an incarcerated family member. Half of the offenders had experienced CSA. Only 20% had no ACEs, compared to 35% of the general female population, and 41% had four or more ACEs, compared to 15% of the general female population (Levenson et al., 2015).

Another 2014 ACE study found that 670 male sexual offenders, compared with men in the general population, had more than three times the odds of CSA, emotional neglect and coming from a broken home (homes where mum and dad split or divorced); twice the odds of physical abuse; and 13 times the odds of verbal abuse. Nearly half had an ACE score of 4 or more. Only 16% had no ACEs. Multiple forms of maltreatment often co-occurred with other household dysfunctions, suggesting that many sex offenders were raised in a turbulent social environment (Levenson et al., 2016).

A 2014 study in eight Eastern European countries including 10,696 young adults (18–25 years, 59.7% women) found increased risk of health-harming behaviours, with Odds Ratios (OR) varying (or ranging) from 1.68 CI [1.36–2.15] for physical inactivity to 48.53 CI [31.98–76.65] for attempted suicide among those reporting four or more ACEs compared to those without ACEs. (Bellis et al., 2014).

Other Relevant Studies

A 2010 meta-analysis including 59 studies compared male adolescent sex offenders (n = 3,855) with male adolescents with no sex offences (n = 13,393) in antisocial tendencies, childhood abuse, exposure to violence, family problems, interpersonal problems, sexuality, psychopathology and cognitive abilities. Ranked by effect size, the largest group difference occurred for atypical sexual interests, followed by sexual abuse history, criminal history, antisocial associations and finally, substance abuse (Seto & Lalumière, 2010).

A 2013 systemic literature review including 65 publications found child abuse, substance abuse and parental divorce to be frequent risk factors for poor mental health in adulthood. Emotional, sexual and physical child abuse were key risk factors for depression. CSA and family violence were the greatest risk factors for anxiety disorders. Family violence and physical neglect were strongly correlated with substance abuse (De Venter et al., 2013).

A 2015 systematic literature review of the relationship between ACEs and sleep disturbances, with a focus on adult women, identified 30 publications (28 retrospective studies) with heterogeneity in the types of ACEs and sleep outcomes measured. Most (n = 25) of the retrospective studies documented statistically significant associations between the number of ACEs and sleep disorders. This association was verified by two prospective studies. Further, the associations between family conflict at ages 7–15 years and insomnia at age 18 years (OR = 1.4, CI [1.2–1.7]) and between CSA and sleep disturbances 10 years later in adult women ($\beta = 0.24$, $p < 0.05$). were statistically significant (Kajeepeta et al., 2015).

A 2016 cross-sectional survey including 318 people receiving community mental health care found 63% of men and 71% of women reported childhood maltreatment. About 46% of men and 67% of women reported domestic violence and 22% of men and 62% of women reported sexual violence, both in adulthood.

Overall, people with mental health issues and experiences of childhood maltreatment were two to five times more likely to report domestic and sexual violence in adulthood (Anderson et al., 2016).

A 2016 prospective longitudinal study following 332 persons (52.4% male) from childhood (18 months–6 years old) to adulthood (31–41 years old) looked at parent-reported physical and emotional abuse and child-reported sexual abuse. Adult outcomes included three groups: (1) low risk of substance abuse, depression and anxiety; (2) moderate substance abuse risk and mild depression and anxiety and (3) moderate substance abuse risk and moderate to high depression and anxiety. Physical abuse increased adolescent depression but not the adult outcome groups. Children exposed to severe emotional abuse had higher risk of comorbid substance abuse, depression and anxiety into their mid-30s. Sexual and physical abuse had more proximal effects on adolescent alcohol use and depression, which then influenced the risk of adulthood problems (Skinner et al., 2016).

A 2017 study including a national sample of 2,244 young Swedish adults with at least one ACE found that physical assault, neglect and witnessing violence as a child were significantly associated with adult criminal behaviour, but not experiences of property, verbal or sexual victimisation (Howell et al., 2017).

Studies With a Focus on CSA Survivors

A European study from November 2015 to October 2021 included 6,000 survivors of CSA who shared their experiences as part of an independent inquiry. Out of the 6,000 survivors, the 5,440 accounts analysed at the point of writing, 1 in 10 talked about an experience of CSA for the first time. Around two-thirds did not tell anybody about the CSA at the time it happened. Around 88% described an impact on their mental health, with more than a third reporting depression and 45% indicating an illness or condition that affected their day-to-day life (Berrymans Lace Mawer, 2021).

A 2017 study included 484 adult CSA survivors (86% female) treated by the Danish Victims Foundation (http://www.offerfonden.dk) over an 18-month period. The exclusion criteria were (1) intoxication, (2) psychotic disorder, (3) self-harm and (4) treatment elsewhere. The mean age was 36.1 years (range: 18–70). Most participants (91%) had experienced CSA before the age of 15, committed by a person at least 5 years older and occurring an average of 23.5 years ago. The average age that abuse started was 6.6 years, and it lasted for an average of 6.9 years. About 8.5% had experienced abuse once, 22% 2 to 5 times, 21.4% 6 to 15 times, 22% 16 to 50 times and 26.4% 51 or more times. Twenty-five percent had been sexually abused by more than one person. Multiple abusive acts were associated with anxiety, somatoform disorder, drug dependence, PTSD and major depression. The co-occurrence of CSA and childhood physical abuse was associated with increased risk of alcohol dependence (OR = 2.89). The presence of more than one abuser in childhood increased the risk of PTSD, major depression, anxiety, somatoform, dysthymia and thought and delusional disorders by two to four times. Women were more likely to be diagnosed with a somatoform disorder, whereas men were more likely to be diagnosed with dysthymia and substance dependence (Elklit et al., 2017).

Moving Towards More Participatory and Inclusive Research

In most of the research reviewed here, the researchers determined the research focus, design and process, whereas the study population was a passive target.

In participatory research, the target population becomes involved as a partner to varying degrees: manipulation, tokenism, consulted and informed, assigned but informed, externally initiated and shared decisions with the target group, initiated by the target group and shared decisions with the external partner, and initiated and directed by the target group. Participatory research enables informed research because the people who have experienced child maltreatment contribute to knowledge sharing and production on the topic.

Most current globally initiated child health research rarely reaches beyond consulted and informed.

An example from the category of ‘externally initiated and shared decisions with the target group’ is a study from 2001 that used focus groups and thematic analysis to learn what children and adolescent CSA survivors believed counselling and therapy should entail to help them and how others (e.g. parents, social workers, law enforcement and siblings) might have helped them better (Nelson-Gardell, 2001).

In January 2021, the Council of Europe created a handbook for children’s participation, developed with the participation of children and including nine basic requirements for effective and ethical participation: (1) transparent and informative, (2) voluntary, (3) respectful, (4) relevant, (5) child-friendly, (6) inclusive, (7) supported by training for adults, (8) safe and sensitive to risk and (9) accountable (Council of Europe, 2021).

Save the Children, which has decades of experiences in ‘rights-based approaches’, has developed two manuals for research with children, youth and adults.

The first, *Children in Focus: A Manual for Participatory Research with Children* (Boyden & Ennew, 1997), provides practical and ethical guidance on how to conduct research with children including participation, child-centred and conventional research methods and child-focused research tools. The manual was developed based on broad cooperation with children, youth and adults in Bangladesh, Ethiopia, India, Nepal, Pakistan, Sri Lanka and Uganda. Some of the methods were field tested in Kenya (Boyden & Ennew, 1997).

The second, *A Kit of Tools for Participatory Research and Evaluation with Children, Young People, Adults: Compilation of Tools Used during a Thematic Evaluation and Documentation on Children’s Participation in Armed Conflict, Post Conflict and Peace Building* (Save the Children, 2008), is based on practical experiences from Bosnia-Herzegovina, Guatemala, Nepal and Uganda. A key feature is its use of formative dialogue research and child-friendly tools to allow for active involvement of children as advisors, peer researchers, active respondents, development workers, peace agents and documenters (Save the Children, 2008).

Save the Children has moved towards more inclusive research (from child- or youth-initiated with shared decisions with adults to child- or youth-initiated and directed).

Inclusive research is a term originally established in the early twenty-first century alongside the closure of large institutions for people with learning disabilities (Buchanan & Walmsley, 2006). Inclusive research is illustrative of changing ideas about people with disabilities from incompetent and burdensome 'objects of charity' to people with rights and potential to learn and contribute. Inclusive research is part of a wider rights movement, known by the slogan 'Nothing about us without us'. It has been adopted in work with children, young people and others (Welshman & Walmsley, 2006).

Inclusive research changes the hierarchy of traditional research configurations, which view professional researchers as expert and commentators on the lives of those positioned as the subjects of research. Inclusive research privileges insider accounts from experts by experience and results in less rigid hierarchies and a sense of research as a shared journey.

Inclusive research (1) is owned by lay people; (2) furthers the interests of lay people, with researchers on their side; (3) is collaborative; (4) enables lay people to exercise control over the process and outcomes and (5) produces outputs that are accessible (Walmsley & Johnson, 2003). A manual for inclusive research has been developed by Jönköping University in Sweden based on an Australian manual for inclusive research practice with the autism community (CHILD, n.d.).

Key Findings, Discussion, Conclusions and Recommendations

Violence is a major public health problem. Every year, an estimated 1 billion children from 2 to 14 years old are victims to violence. Child maltreatment is an important societal problem with far-reaching health and socioeconomic consequences that take an economic toll on countries throughout the world.

The global availability of data on child maltreatment is sporadic, with low validity and reliability, and cost-effective evidence-based interventions remain to be identified (World Health Organisation, 2016). Few global experts have consulted and involved the survivors of child maltreatment in an attempt to provide a more comprehensive picture of reality and guide priority setting and strategy development. But changes might be on the way; during the production of the *World Report on Violence against Children*, children were 'listened to, heard and respected' (Pinheiro, 2006, p. XIX), and the Committee of European Ministers embarked on a more consultative process involving children when it developed a recent strategy to advance the protection and promotion of the rights of the child across Europe (Council of Europe, 2022).

However, regarding research on child maltreatment, inclusion is only in its infancy. This literature review did not identify research studies designed by survivors for survivors. However, a few intervention projects exist, mainly aiming to help female survivors of violence. Knowledge about and interventions for men and people of other genders are limited. This review identified one promising project, ‘Survivors & Mates Support Network (SAMSN)’, founded in Australia in 2010 by men for male CSA survivors. The project runs support groups for men who have been sexually assaulted as young boys or adolescents. It includes men of different cultural, religious and sexual orientation but has no research component (https://www.samsn.org.au/get-to-know-us/).

Researchers like Kempe, Herman, Bessel, and Felitti and others have made valuable contributions to our present knowledge about childhood maltreatment and initiated the development of research tools for measurement of ACEs and structured interviews (http://www.traumacenter.org; Luxenburg et al., 2001). But we still have far to go.

We need to improve the present research tools to enhance our measurement accuracy and move our research questions from ‘What is wrong with you?’ toward a more curious and inclusive ‘What happened to you?’ (Winfrey & Bruce, 2021).

We need to see survivors of child maltreatment as experts by experience to be included in research and empowered to initiate research by them for them.

Present research on child maltreatment has mainly been done on survivors, who are invited to participate in already designed projects. To be inclusive in design, future projects need to be designed, implemented, analysed and disseminated by survivors of child maltreatment in close cooperation with researchers. Likewise, all national and international strategies, plans and policies aiming to address maltreatment need to start with the true experts: the survivors of child maltreatment.

Youth and adult survivors of child maltreatment are often traumatised by the experience. Therefore, it is important that all research including survivors of childhood maltreatment follow the principles of trauma-informed approaches to prevent retraumatisation and enhance capacity building: (1) promote a sense of safety, (2) approach decisions with transparency and enhance trustworthiness, (3) develop and strengthen peer support, (4) ensure collaboration and mutuality to contribute to healing during the process, (5) embrace survivor-centred approaches that empower the survivors and give them a voice and choice and (6) ensure efforts are culturally, historically and gender sensitive and free of prejudices based on bias and stereotypes (SAMHSA’s Concept of Trauma and Guidance for a Trauma-Informed Approach).

There is a need for more trauma-informed, inclusive research initiated by survivors for survivors of childhood maltreatment – research that strengthens local research capacity building and inform policymakers from the bottom up, including experts by experience.

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Chapter 14

Art and Action: What Participatory Action Research With Adult Survivors Must Address

Alex Stern and Jolka Nathanaili-Penotet

Abstract

Through research on child sexual abuse (CSA) and adult survivors, knowledge is gained. This knowledge might support decisions – whether political, professional or otherwise – that affect the lives of children who are victims of CSA and adult survivors. Additionally, this knowledge influences what the public knows about CSA and adult survivors and as a consequence, how child victims of CSA and adult survivors are treated in everyday life. Given the huge impact research can have on survivors' lives, this chapter raises the question of what aspects of CSA and survivorship are relevant for survivors from survivors' perspective and whether these aspects can be addressed by Participatory Action Research (PAR) as a research paradigm. To identify relevant aspects, survivors' artwork is analysed because art is a way to contribute to public discourses with very little regulation. For analysis, the Sociology of Knowledge Approach to Discourse is used. In this chapter, we introduce basic theories of knowledge from a constructivist perspective in a short background section and explain the aim and method of analysis. Afterwards, we present some key aspects of survivors' art on CSA and survivorship: The invasiveness of CSA, speech, the symbolic violence behind physical abuse and issues of injustice and responsibility are discussed. Additionally, the discursive relation between artists and audience is of interest to finally answer whether – and, if so, why – PAR is an appropriate research paradigm to address these aspects.

Participatory Research on Child Maltreatment with Children and Adult Survivors, 229–245
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Keywords: Adult survivors; child sexual abuse; participatory action research; art; activism; epistemic injustice

Introduction

Through research on child sexual abuse (CSA) and adult survivors, knowledge is gained. This knowledge might support decisions – whether political, professional or otherwise – that affect the lives of children who are victims of CSA and adult survivors. Additionally, this knowledge influences what the public knows about CSA and adult survivors and as a consequence, how child victims of CSA and adult survivors are treated in everyday life. Given the huge impact research can have on survivors' lives, this chapter raises the question of what aspects of CSA and survivorship are relevant for survivors from survivors' perspective and whether these aspects can be addressed by Participatory Action Research (PAR) as a research paradigm. To identify relevant aspects, survivors' artwork is analysed because art is a way to contribute to public discourses with very little regulation.

Theoretical Background: What Is Knowledge and Why to Look at Art

From a constructivist perspective, all social life and perceptions of (social) reality is based on and structured by shared knowledge – e.g. roles and social norms – and the division between everyday knowledge and special knowledge (Berger & Luckmann, 2013). Special knowledge is not available to everybody. Instead, it is developed, evolved and provided by specialists, who have the appropriate legitimation (e.g. official plumber's training to fix bathroom installations or an academic degree to give a methods lecture). Specialists of one area have to prove to laypersons (anyone who is not the same type of specialist) that their specific area contains enough abstract knowledge and that it is important enough to require specialists. By dividing knowledge into special and everyday knowledge, through (de)legitimisation and reproduction of knowledge, social actors (e.g. people or organisations) negotiate constantly about which knowledge is broadly accepted as 'reality' and who knows this area best (Berger & Luckmann, 2013). If this negotiation includes complexes of statements on the same or adjacent subjects and takes place with formalised (and formalising) claims to validity, it is a discourse (Keller, 2011).

Knowledge and its relevance or legitimacy is not only gathered, reproduced or negotiated on a verbal level. As Bourdieu (1998) has shown using gender as an example, knowledge about social norms and practices is not always verbalised or able to be verbalised: As it is incorporated, it affects people on a physical level of existence. Incorporated knowledge as part of a person's habitus (a system of categories of perceptions, thoughts, actions and appreciations; Bourdieu, 1979) is usually based in social norms and the person's role. Furthermore, it reflects the person's position in the web and intersections of social dimensions of power (e.g. if caring for guests in private spaces is only required from women, they may do so without thinking about it). The less this broadly shared and incorporated knowledge is verbalised, the more the physical practices associated with it are considered to be ‘natural’ on a biologic level (e.g. the motivation to care for guests is considered as linked to female sex over time). Thus, as social norms are inscribed in a person’s physical existence and practices and become invisible as something social, the dynamics of power, oppression and violence linked to those norms become invisible. At the same time, these dynamics – labelled symbolic violence by Bourdieu – are reproduced each time social actors refer (automatically) to them in everyday performances and decisions, and they continue to shape the common idea of reality. Altogether, symbolic violence is a type of violence that is woven into everyday life’s structure, common performances, actions and spaces, thus dividing dominating and dominated groups often in a subtle way (though it does not exclude physical domination; Bourdieu, 1998).

From a constructivist position, by sharing and negotiating knowledge, people negotiate what is real and which aspects of reality are important. Additionally, there is nonverbalised, incorporated knowledge that is easily naturalised and stabilises as one part of symbolic violence the dominant social position of one social group. As knowledge – and the shape of social reality – is negotiated, conflicts between different positions arise. In that case, role (specialist or layperson), social power and symbolic violence will determine whose contribution to the specific discourse is taken more seriously. More specifically, epistemic injustice reflects whether someone can engage in shaping our reality. Epistemic injustice includes the marginalisation of people (e.g. women) as knowers and the marginalisation of knowledge as irrelevant, not abstract enough, or not presented in an appropriate style (Fricker, 2007).

In conventional research, participants usually neither decide what portion of their experiential knowledge about themselves or their perspectives is valued as important enough to be transferred into propositional (‘officially accepted’) knowing, nor participate in this transfer, have access to the full results or benefit directly from the process of knowledge transfer (Coleman, 2015). Epistemic injustice explains why the knowledge of marginalised groups, who are typically objects of research, is taken less seriously regarding the shared definition of reality than the knowledge of academics (who are official specialists in generating knowledge). Epistemic injustice leads to the loss of knowledge and is dehumanising and thus, ethically wrong (Fricker, 2007).

PAR tries to solve this injustice in the context of research. PAR can be done in all scientific disciplines that include (refer to or rely on) human action (in relation to other people or the environment) and includes a broad range of methods, outcomes and possible participants. However, there are clear definitions and well-established characteristics of PAR: It is research that ‘is emergent and developmental. It concerns practical issues and human flourishing. Its modality is primarily participative and democratic, working with participants and towards knowledge in action’ (Bradbury, 2015, p. 7). PAR is subject to a strong ethical framework as formulated, for example, in the International Collaboration for Participatory Health Research (2013) guidelines. Given this, PAR is not a research method; instead, it is a research paradigm. PAR is always research with rather than on participants.

In discourses, participants with higher social capital can control single discourse patterns and the whole discourse (Bourdieu, 1998; Keller, 2011). Regarding adult survivors of sexual abuse, the aspect of epistemic injustice is especially critical in context of the long social and legal history to degrade survivors' credibility and frame disclosures as hysteric, for example, in academic milieus (Bourdieu, 1998; Sanyal, 2016). Following these characteristics of PAR, PAR with adult survivors of CSA should reflect, abstract and evolve knowledge into action that is important to adult survivors (and not only to academic researchers). Thus, it is crucial to ask which aspects of CSA and survivorship are marked as relevant from survivors' perspectives. Afterwards, it can be discussed whether PAR could be an appropriate research paradigm to address these aspects.

Method

To analyse what knowledge and which aspects in the broad discourse on CSA and adult survivors are marked as relevant from survivors' perspectives, an analysis following the Sociology of Knowledge Approach to Discourse (SKAD) was performed (Keller, 2011). Discourses are composed of the different elements they convey, such as structures of meaning, patterns of interpretation or systems of categories. In a discourse, certain relations between the individual elements are established, transported and changed in the discourse process (Keller, 2011). Discursive patterns and especially the underlying structures of meaning can provide rich information on the knowledge negotiated in the discourse. Focusing on epistemic injustice, where not only knowledge but also the knower's social position are important to discuss, SKAD is of special usefulness: Among the various discourse-analytic approaches, SKAD belongs to the context- and content-including approaches (in opposition to narrative approaches focusing mainly on content; Telles Ribeiro, 2006). SKAD combines the classical hermeneutic sociology of knowledge with aspects of symbolic interactionism, thus enabling analysis of the discourse's content and the discursive practice (Keller, 2011).

As data material, the artwork of two professional artists who survived CSA was chosen for in-depth analysis. Using art as data to identify relevant discursive elements for a group to which the artists belong might be unconventional. However, in the case of CSA survivors as a group whose knowledge is marginalised, art is the domain least prestructured and interpreted by members of other, more privileged groups. Thus, the authors chose artwork because art typically involves no or minimal external requirements from nonsurvivors regarding and regulating its type and content. This enables results that are less influenced by external discursive conditions, as it would be the case, for example, with interviews or articles that have undergone external editing and have to meet media expectation. Nevertheless, artwork by professional artists is – as are research results – generated to be shown and seen, although usually as a contribution to a public discourse and not a special one as among academic researchers (Keller, 2011). Thus, artists who perform as survivors and artists refer and contribute to collective knowledge, including that of survivors as a social group. The two artists were chosen because they are self-described survivors of CSA and provide open access to a large amount of their work as required to gain enough material. Both artists gave informed permission to use their art as examples and had the opportunity to read this chapter.

Results

Because a full SKAD analysis is extensive, the following subsections only highlight the main results relevant for the aim of this chapter. Altogether, the analysed art covered the areas of violence, mental health and social, political and legal failures and demands regarding responsibility and justice. The highlighted aspects presented after a brief overview of the artists include three discourse patterns, one aspect of narratives and one special aspect on survivor-artists' discursive practice.

Survivors' Art as Data: The Artists

As examples of survivors' art, two samples were chosen whose creators gave open access to full or parts of their art catalogues and statements about their work and who are survivors of CSA. Renate Bühn (2022) is an artist, activist and social worker. Nozibele Meindl (2022a) is an artist, activist and digital multimedia visual artist. Although both artists currently live in Germany, where Bühn grew up, Meindl grew up in South Africa during apartheid. Both artists engage in a survivors' council from Bremen for better implementation of the Istanbul Convention. Meindl describes herself as a 'social commentator, critiquing violence, loss, death and the strength of community in the face of disaster' (Meindl, 2022a, p. 1), inspired, among others, by psychoanalysis and Xhosa culture. Apart from raising awareness overall, through her work, Bühn is 'looking closely at hidden realities' (Koch, 2017), targeting the protection of perpetrators by individuals, organisations and society as well as bystanders' indifference.

Pattern 1: CSA as Invasive Violence

Through her work, Meindl acknowledges her childhood trauma and causes powerful awry and unhealed emotions (e.g. see 'Memento' in Fig. 14.1):

> I live in a perpetual jumble of fear, anger, confusion, hopelessness, despair, depression, shame, guilt and helplessness. I experience severe anxiety and flashbacks, causing me to dissociate from my world. In an attempt to refute assumptions and myths, I am compelled to visually articulate and document my experiences of prolonged grief by unmasking the trauma that has imprisoned me for many years.

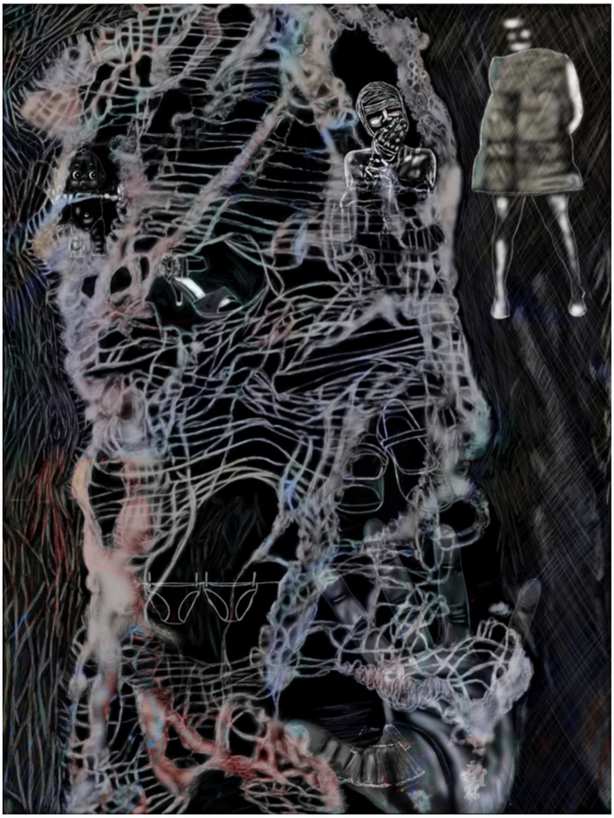

Fig. 14.1. Nozibele Meindl: Memento.

> It is childhood sexual abuse.
>
> … During my twenties, I experienced trauma which caused depression and insomnia. I suddenly recalled my childhood sexual violation (which took place in broad daylight) as a flashback.
>
> (Meindl, 2022b, pp. 7, 11)

Meindl's oeuvre, titled *Workbook* is 'a collage that represents my fragmented self … images to express the effects of trauma on the body and mind, most importantly my self' (Meindl, 2022c, Image 3). In *Workbook*, the viewer is compelled to discern various concepts from a collage of writings, followed by Meindl's statement: 'Notes: the self is the essence and core of who we are. This is formed during the early years of childhood' (Meindl, 2022c, Image 2).

Her elaborations concerning the function of her art and its relation to childhood trauma are inscribed in another collage of handwritten notes:

> Psychological Trauma
>
> Thoughts: The image is my own response to sexual traumatic memories – childhood sexual trauma. When I envision the weight of the traumas, I see it as a gigantic tumor that has invaded my body and has taken up residence in my head. It has tentacles that have hooked deep in my brain, all the way to my heart. The tumor is increasing, needs to be eliminated NOW!!
>
> (Meindl, 2022c, Image 4)

This invasive component of sexual abuse and its long-lasting, sometimes fatal consequences are visual in Bühn's work very directly, too: Her light installation 'In Memoriam' (started in 1997) presents 10 (as of 2022, because the installation is not static and grows from time to time) light boxes with red glass screens showing the names, lifespan dates and causes of death of 10 people. Apart from one murder and one unspecific cause referring to the lack of help for persons fleeing ritual abuse, the boxes name causes of death as heart failure, drugs or medication. At the same time, the additional biographic information given to the audience unmasks that the underlying cause of death was instead sexual violence and 'the ignorance of their families and society in general' (Bühn, 2017).

In several examples of both artists' work, different aspects of the consequences of CSA are visible: First, CSA is not only invasive on a physical but also a psychological level (the 'tumour' Meindl describes in her work), and second, that this can reinvade people's physical health (as shown in 'In Memoriam'). Both artists' work demonstrates the artificiality of the division between physical and psychic levels. As a third aspect, both artists include the dimension of time (e.g. in recollecting on flashbacks, dates of birth and death – or rather, shortened lifetimes) as one dimension of a person's existence influenced by the experience of CSA. The last main component of the discursive pattern of CSA as invasive violence is obvious, for instance, in Meindl's description of the scene where the violence took place ('broad daylight') or several explanatory texts of 'In Memoriam'. It is the social dimension, where bystanders do or do not react, where people are ignored in their struggle to survive the violence and its consequences, and finally, where death leaves others to grief.

Pattern 2: Symbolic Violence

Children's struggle with ongoing abuse is shown, for example, in Bühn's (1999) 'Breakfast with Daddy', where two slices of breads with honey are prepared at an empty table as for breakfast (see Fig. 14.2). Only, the honey is covered with dead flies, making visible the daily struggle that children face through everyday contact with their abusers and who have to survive the contradictoriness of the sexualised violence and the perfect façade (Bühn, 2017).

The subtle symbolic violence (Bourdieu, 1998) under the layers of obvious physical violence is another pattern that occurs frequently in both artists' work. One might state that CSA is everything but subtle. However, taking into account,

Fig. 14.2. Renate Buehn: Breakfast With Daddy.

for example, the power of adults over children and shared ideas of blaming the victim, downplaying other practices of adult violence against children or sexist stereotyping of children regarding their assigned gender, CSA is one social practice inlayed in age- and gender-based symbolic structures. For instance, one might imagine Bühn's 'Breakfast with Daddy' as the very situation in which a child has to conquer or dissociate from all disgust and eat their breakfast, regardless of whether their rapist is sitting in front of them, because traditional roles demand children to eat their breakfast at the time their parents have set.

Following Bourdieu (1998), one main aspect of symbolic violence is the opposition in which dominating and dominated persons live. Both refer to the same structure – where one is dominating the other. One crucial result is that both parties in the shared structure will usually not recognise the structure behind its outcomes once it is incorporated. Thus, both the dominant and dominated will reproduce the structure and re-establish their position within it (Bourdieu, 1998).

In this context, Meindl's (2022b) testimony sheds light concerning the incorporated structures of domination exerted towards her (through the complicity of the other, her mother):

> I remember my mother, the epitome of a good submissive Christian matriarch, was prohibited from expressing any emotional response to her daughter's sexual assault. I recall her calm demeanour as she rushed my twin sister and I to the hospital, where our violation was confirmed. The look of devastation and grief on her face was unmistakable.

> In our patriarchal society, any form of abuse is regarded as a private matter – concealed and 'contained' within the family. A girl child was expected to discourage attention from boys and men. The child is blamed, and the assault is seldom reported to the authorities. This silence endorses the belief that child abuse is justifiable, countering any investigation into the consequences (Riggs 2010).
>
> The 'incident' was never discussed again. (p. 11)

The dominating party can define what is going on. This power of perpetrators who profit from dominant positions (e.g. being male in a patriarchy, an adult in opposition to a child) is shown in both artists' work as linked to the dimensions of the pattern first presented – e.g. visible in the aspect of the physically hurt and examined child, who is held responsible for what has happened.

Narratives: Reclaiming Words

On the discursive level of content, speech, speechlessness, silencing and the perpetrators' language appear frequently. This is especially the case when symbolic violence is addressed. The dominated can only speak (or keep silent) about their situation in the dominating one's language. When Meindl refers to these structures described, she shows the extent to which this can grow when CSA is downplayed as an 'incident' or when children's ability to speak out is taken, as in 'I want to tell you a secret' (Fig. 14.3), where the children's mouths are wiped out.

As does Meindl, Bühn integrates the language of the dominant – the perpetrator – in her artwork without using it the way supposed by dominant perpetrators or accomplices. In the *Lavabo* series (2014; see Fig. 14.4), Bühn cites the sentence 'Lavabo inter innocentes manus meas' ('I will wash my hands in innocence') from the extraordinary version of the Roman rite performed by a priest during Mass. The sentence is formed by about 4,000 metal pins stuck into a lavabo towel, making visible the large number of victims of sexual abuse in the Catholic Church.

> Every case of sexual assault and likewise every instance of someone turning a blind eye to the issue, of looking the other way, of denying, covering up or downplaying it, tears holes in the flesh of victims-survivors, tears holes in family life, the church and society.
>
> (Bühn, 2017)

The language used by perpetrators of the Catholic Church as an organisation is not only uncovered as the dominants' voice embedded into the structures of abuse but also destroys.

Both artists show how children are silenced, adults are unwilling to listen and the only language available to discuss CSA has been that of symbolic violence

Fig. 14.3. Nozibele Meindl: I Want to Tell You a Secret.

that protects the perpetrators. The narrative of speech(lessness) is used in direct (children without mouths), subtle (mother adopting silencing) or cynical (Catholic quotes) ways. On a nonnarrative, meta level, the artwork is a way to reclaim the opportunity to speak – as Bühn states: ‘art as a form of resistance, as a means of finding language’ (Koch, 2017).

Pattern 3: (In)justice and Responsibility

Injustice, justice and responsibility form another discursive pattern essential in both artists’ work. Although both patterns use the narrative described, making symbolic violence visible (as in Pattern 2) is one focus, and asking questions of (in) justice is another. Meindl’s work goes beyond mere description of symbolic

Fig. 14.4. Renate Buehn: Lavabo.

violence, adding an ethical component to the art – the children who 'want to tell you a secret' but are silenced and stare at someone, as well as the 'internal witness' (Meindl, 2022b) or the other children pictured. Wounds shown in Meindl's work are not cared for; instead, tumorous tissue can grow untreated (Meindl, 2022b). As Meindl describes in her artwork, responsibility is shifted to victimised children, who have to deal with the sequelae of CSA alone.

Bühn, too, encourages her audience to empathise with the unjust situation of children who have to survive ongoing abuse, the social and legal situations survivors might face, and their anger and fights against injustice. For example, 'In Memoriam' describes – as partially detailed – how those remembered tried to protect themselves and others from their perpetrators and how the legal system acted nonsupportive and where social support was missing. The *Lavabo* series includes not only cynical quotes regarding the perpetrators but also the lack of responsibility the Roman Catholic Church as an organisation has shown until today. Other works address the few perpetrators convicted for CSA and the public disinterest. Bühn demands ‘of this society, from a feminist standpoint, that it listen, open its eyes, and overcome its willful ignorance’ (Koch, 2017).

Discursive Practice: The Artist and the Audience

On the level of discursive practice (how the artists contribute to public discourses on CSA and survivorship), the relationship between the artist and the audience requires a closer look. The discursive elements discussed here affect the audience in other ways than, for example, a city major’s public speech at a newly opened shelter.

Regarding the three discursive patterns previously mentioned, one aspect is the emotion-inclusive way the artists describe CSA and its (invasive) consequences for an individual’s life and society. For instance, Meindl creates an inversion at the level of the viewer, such that the exposure to the artist’s internal pain provokes an abhorrent feeling as part of CSA sequelae, which leaves the viewer speechless. She explains that:

> The purpose of the first video artwork is twofold: to document the transformative force of grief over time, where the victim is unaware of the subtle changes in personality and behaviour and further, is powerless against them. I draw the viewer’s attention to my silent pain and simultaneously critique their role as spectators, voyeurs, or passive witnesses.
>
> (Meindl, 2022b, p. 17)

In other artwork, Meindl and Bühn seek to make their audience feel disgust, silent terror or anger. By this (and by the integrated or accompanying verbalisation), the artists give people without any experience of CSA the chance to empathise on more than only an intellectual level. By this, they turn the audience into witnesses of CSA (Emcke, 2013). Both continue with this mediation also outside the creation of art. Both Bühn and Meindl engage in, alongside the creation of artwork, (activist) education and empowerment of younger people for a more understanding, empathic and diversity-aware world (Blaxmag, 2022).

To transfer the experience of CSA and its consequences for children and adult survivors into artwork not only enables nonsurvivors to empathise but also empowers and enables other survivors to speak about their experiences because the artwork provides them with a language to adopt. Through their art, survivor-artists develop (readable, visible or audible) expressions for violence – including the symbolic violence in and underneath CSA.

This is crucial also on the societal level: The structures of symbolic violence (who dominates whom, and how) in a society are usually stable, but neither static nor unchangeable. Here, Bourdieu (1998) introduced the idea of symbolic transformation to change those structures. Before any changes on the level of social structures can occur, the transformation needs to take place at the level of the individual. As mentioned, the structures of symbolic violence are incorporated and not recognised easily. That said, one needs to be aware of the role of domination in everyday life, in one's mindset and physical self-expression (Bourdieu, 1998). Regarding CSA and survivorship, survivors' art, such as Meindl's and Bühn's work, makes these structures visible to the audience.

Survivors-artists' actions and oeuvres aim to expand the sphere of empowerment by proposing that private family matters become public agenda, expressing socially disturbing raw emotional responses, and breaking social cycles of shame and blame. They demand their audience to pay attention to creepy oeuvres, which distribute responsibilities in communities by making room for the victim's or survivor's perspective. Thus, they act by speaking about the unheard conversations in communities and pushing the survivors' discourse forward into the public arena.

These acts of symbolic transformation can be taken literally, such as when Bühn engages her audience or other survivors to participate in her artwork. For example, during the German Catholic Congress in 2016, Bühn and other survivors carried posters highlighting the *Lavabo* series (2016), printed with excerpts and survivors' quotes from the investigation into child abuse in the Catholic Church, through the streets where the gathering took place. Later that year, survivors who attended the MitSprache Congress in Berlin, Germany, joined her in carrying either those posters or pictures of child victims of the Catholic Church provided by Barbara Blaine, an American activist, for a spontaneous commemoration in front of one of Berlin's most tourist-frequented churches (Bühn, 2017). It has to be mentioned that survivors' art, as with other artists' work, does not need to be directly connected to the context of the abuse the artist experienced, and activists' work is often performed in collectives. Not every person joining her has to have survived sexual abuse by priests or nuns as perpetrators. Nevertheless, Bühn and her accompanying survivors decided to confront the public sphere together as a collective.

Discussion: Is PAR the Right Research Paradigm?

Focusing knowledge on CSA and survivorship and the discourses where both are negotiated, the public discourse (for everyone) and the special discourse (among scientists and professionals as specialists) are visible (Keller, 2011). Both are relevant regarding the actual situation of children, adult survivors and their allies. Political decision-making and press contributions to the public discourse usually draw on special knowledge provided by professionals and far more often, researchers. Thus, researchers of CSA and survivorship are in a powerful position regarding public education and political decision-making on sexual abuse and survivorship. Their special knowledge can support decision-making that changes children's and survivors' lives.

Survivors' knowledge by experience is classically marginalised knowledge because survivors are marginalised as unreliable knowers, often framed as hysterical and irrational (Fricker, 2007; Sanyal, 2016). However, the analysed art shows that survivors:

- define very different aspects of CSA and survivorship as relevant (e.g. [in]justice or the mentioned invasiveness);
- reclaim or develop unique wordings and expressions regarding CSA and survivorship that are not part of (violent) pre-existing structures (anymore);
- gather, abstract and transfer knowledge and
- engage in all of this with the motivation to change social structures.

Some of those aspects are illegitimate from the perspective of classic research: Nonacademic survivors lack the formal competence to determine relevance – for example, regarding a research question (Coleman, 2015). Either their knowledge is illegitimate if it is based on experience rather than academic study or they are supposedly too subjective and emotionalised to be accepted as knowers (Ahmed, 2012; Fricker, 2007). PAR tackles all of these issues because it is a fundamental aspect of this research paradigm that academic researchers share their power to define what is relevant and accept participants' knowledge as legitimate and of the same worth as their knowledge (Coleman, 2015). This includes nonacademic (e.g. survivors) and academic researchers developing appropriate wordings and definitions and gathering and evolving knowledge together (Coleman, 2015; Wright, 2021).

Survivors' art highlights the invasiveness of CSA and its impact on various aspects of survivors' lives. This includes the social and emotional dimensions. To consider both in research without degrading emotions or the complex social context of human existence as nonabstract or irrational, research methods and types of outcomes have to be chosen or developed together between survivors and academic researchers. This can result in creative, art-based methods to gather data, as performed by researchers and Mayan women during a research project (Lykes & Scheib, 2015), that enable the respectful inclusion of emotions. Considering the social dimension of CSA sequelae, PAR usually relies on groups of nonacademic participants. This works either with pre-existent communities, such as in the development of cultural healing programmes for Aboriginal survivors of institutional CSA (Black et al., 2019), or by establishing a group for a research project, as in Lykes and Scheib (2015).

Symbolic violence is another main pattern negotiated in survivors' art. In PAR, reflection and prevention of symbolic violence towards nonacademic participants is one key feature. Ensuring that violent structures are not reproduced in the research project requires preventive measures, such as in the cultural healing programme development, where all decision processes were formalised in balance among survivors or academic researchers or in favour of survivors (Black et al., 2019). PAR usually reflects dimensions of symbolic violence not only between academic and nonacademic participants but also and especially on other axes of social marginalisation – e.g. racism or gender (Black et al., 2019; Lykes & Scheib, 2015). These intersections of various dimensions of marginalisation and symbolic violence are reflected in the artists' work, too. Making them visible is an achievement that art and PAR share.

Following this, symbolic transformation – the change in structure towards more social justice – is the focus of both artists' work and inherent to PAR (Bradbury, 2015). In PAR and art, the extent of the action taken might vary. In PAR, it might vary among the mere co-researching of survivors and academics, changes to the public or community sphere or larger collective action like an international court case (Lykes & Scheib, 2015; Martin, 2015). Both PAR and survivors' art negotiate responsibility: the latter as something required by society and more direct, by the witnesses of CSA, including the audience. PAR reflects the responsibility that comes with discursive power and academic privilege in an epistemically unjust world by sharing this power with nonacademic participants (Coleman, 2015; Fricker, 2007). PAR also uses the power of scientific contributions in discourses, thus combining the empowerment of the nonacademic participants and the specific aims with the (discursive) 'top-down' outcome.

Altogether, we conclude that PAR is an appropriate research paradigm for research on CSA and survivorship from a constructivist and ethic-focused perspective. From this perspective, PAR should be preferred over classical research, if possible. However, given the number of dimensions in which symbolic violence can lead to complications, in several settings, the level of survivor-led research as one step further might be required – e.g. after colonial abuse of the survivors' group by the academics' culture (Black et al., 2019).

Conclusion

PAR holds great promise to gather and improve knowledge on CSA and survivorship by ethical and nonviolent ways of research. PAR can take up, include and (maybe) evolve all highlighted discursive aspects from survivors' art. Action can generate knowledge, and knowledge can generate action – and because lasting social changes can only be done by communities and never by single individuals (Bourdieu, 1998), it is only natural to gain the knowledge collaboratively, too. Survivors' art makes the audience become witnesses of the violence and thus, they become responsible to react. Researchers as powerful contributors to survivors' discourse can show this responsibility by sharing their discursive power with survivors, whose whole lives are affected by the society's discourse about survivorship. Engaging in participatory research, academic researchers and survivors can identify and analyse relevant areas together and develop theories and strategies to target, for example, mental health aspects defined as relevant by survivors, but also underrated social, political or legal issues. Adult survivors have experienced and survived domination by others. On the level of discourse and indirectly, its effects on survivors' lives, it is up to researchers to show awareness of privilege and marginalisation and engage in research practices that not only promise results with high relevance for survivors but also contribute to social justice.

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Chapter 15

Self-Organised Research by Child Sexual Abuse Survivors: Developing a New Research Approach

Thomas Schlingmann

Abstract

The process of knowledge production is usually assigned to scientists who use specific methods to extract knowledge from someone else's experience. Usually this includes collecting, aggregating and interpreting data from an uninvolved point of view; that is, from the outside. This procedure is supposed to guarantee objectivity and generalisation. Many child sexual abuse (CSA) survivors reject such an approach that turns them into objects again. This presents a problem for research because it limits the number and contribution of potential participants and can lead to bias. In self-help groups of CSA survivors, an enormous amount of experiential knowledge accumulates, and sometimes this is transferred into more than only individually valid knowledge. Based on this experience and aiming for more agency of CSA Survivors, a group of adult survivors and researchers developed a new approach to research. It focuses on the development of self-organised research, which enables survivors of sexualised violence to practice research without losing agency. They are indispensable and elementary parts in all phases of the process. This chapter shows one way of formalising this process so quality criteria can be developed and applied. Following the presented approach, evaluation of the presented methods is the appropriate next step because self-help groups give reason to estimate significant outcomes. These outcomes not only enable self-help groups of CSA survivors to incorporate new methods but also include the chance to empower adults, children or youth who have been victims of sexualised violence.

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Keywords: Child sexual abuse; self-help groups; survivor-controlled framework; survivor-controlled research; self-organised research; agency in research

Introduction

Self-Help and the 'Survivor-Controlled Approach'

Sexualised violence in childhood (also termed child sexual abuse, or CSA) leaves a long wake of consequences for those with such exposure. Many affected people deal with lower self-esteem and are very sensitive to being ignored, overlooked or treated as a mere observation object. Self-help groups of adult survivors play an important role in coping with these consequences and are an effective means of self-empowerment.

Such self-help groups for survivors of sexualised violence in childhood have been established in Berlin since the 1980s. Initially, they were women's groups, and men's groups followed later (Autorengruppe Tauwetter, 1998; Birresborn & Sandrock, 1993; Hentschel et al., 1992; Sack & Tauwetter, 1996).

These groups were mostly organised by two Berlin-based counselling centres for survivors of sexualised violence, Wildwasser for women and Tauwetter for men, which were founded by CSA survivors. In 2004, they developed the 'survivor-controlled approach' (Wildwasser et al., 2004), a programmatic foundation for their work with and as CSA survivors. At the centre of this approach is the idea that regaining agency is the essential core of recovering from CSA (Arbeitsgruppe bkA, 2006).

The term *survivor-controlled approach* is a deliberate reference to survivor-controlled research, which came to Germany from the English-speaking world (Russo, 2012).

Survivor-Controlled Research or Participatory Research?

Survivor-controlled research began in Germany in 2002 with a research project on homelessness and psychiatry from the perspective of survivors (Russo & Fink, 2003). It was embedded in a critique of the biomedical understanding of mental health and the division of roles in mental health research (see Sweeney et al., 2009).

The critique of the distribution of roles in research and the reduction of research participants to an object of research has been repeatedly renewed (Schlingmann, 2015). At the same time, scholars noted that research on sexualised violence was truncated in many places by a reduction to trauma research (Schlingmann, 2016). It became clear that Morus Markard's (2007) criticism of experimental-statistical approaches also applied here:

> The problem of experimental-statistical approaches in the social sciences and psychology is that, in the full sense, the concept of experience only applies to those working scientifically, while the

> experience of those being studied is methodologically regulated to the point of being – in Adorno's words – "annulled" (1972, 69) – or, in Marx's words: the "testimony of the senses ... is reduced to the sensuousness of geometry" (1953, 330). (p. 5)[1]

The need for participatory research on sexualised violence was emphasised first in the Bonn Ethics Declaration (Poelchau et al., 2015), which was developed in the framework of the Bundesministerium für Bildung und Forschung (BMBF, or the Federal Ministry for Education and Research) funding line on sexual violence against children and adolescents in educational contexts, and later more explicitly in the 'Memorandum on Participatory Research' (Bahls et al., 2018), which was also developed in this context.

However, a short review of existing research on the topic of sexual violence showed a huge difference in the degree of participation. Wright et al. (2010) developed a model to assess the extent of participation in research and distinguished among forms of nonparticipation, preliminary stages of participation, participation and beyond participation. In their eyes, participation only occurred when the question of decision-making power was tackled. This position was backed by Brenssel and Lutz-Kluge (2020):

> The claim of participation can only be realized in the research context if it is backed up by an interest in taking responsibility, reflection on one's own positioning, a critical examination and the intention to change – also – structural power relations. (p. 12)[2]

Most research projects in the BMBF funding line achieved only the preliminary stages of participation at best; some declared interviewing survivors for data collection as a form of participation. Only a small group of researchers who had worked in the field before tried to implement participation in their research.

An assessment from participatory health research was confirmed:

> The central feature of the Participatory Health Research is the direct participation of those people in the research process, whose working or living conditions are the subject of the research. This

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[1] Quotes originally in German were translated into English, and the original German source is in the footnotes. *'Das Problem experimentell-statistisch verfahrender sozialwissenschaftlicher und psychologischer Ansätze besteht nun weiter darin, dass im Vollsinne der Erfahrungsbegriff nur für die wissenschaftlich Arbeitenden gilt, während die Erfahrung der Untersuchten methodisch reguliert bis – mit Adorno gesagt – » annulliert « (1972, 69) wird – oder mit Marx formuliert: das » Zeugnis der Sinne ...zur Sinnlichkeit der Geometrie « verkürzt wird* (1953, 330)*'* (Markard, 2007, p. 5).

[2] *'Der Anspruch von Partizipation kann sich im Forschungskontext nur dann einlösen, wenn dahinter ein Interesse an Verantwortungsübernahme, Reflexion der eigenen Positionierung, eine kritische Auseinandersetzung und Absicht zur Veränderung von – auch – strukturellen Machtverhältnissen steht'* (Brenssel & Lutz-Kluge, 2020, p. 12).

> does not mean people as test subjects or study participants in a research project, but as research partners on an equal footing.
>
> All research partners jointly determine the core elements of the project, from the selection of the research focus to the selection of methods, data collection and interpretation of the results. Experience at home and abroad show that participation in this sense is rich in prerequisite-rich and therefore often difficult to realize.
>
> (Wright, 2021, p. 140)[3]

Disappointed by the slow implementation and yet encouraged by the development of the 'Bonn Ethics Declaration' and the 'Memorandum on Participatory Research', a group of CSA survivors developed the idea to no longer wait for a majority of researchers to take participation seriously but to take the initiative.

In 2018, the idea of going beyond participation and building an alliance between scientists and survivors for joint research was presented in a conference keynote by Schröer and Schlingmann at a meeting of the BMBF funding line. Schlingmann (2018) proposed to replace the pyramid-shaped stages of participation developed in public health research (Wright et al., 2010) by a two-winged model, which allows participation of survivors in academic research, participation of academics in survivor-controlled research and as a third type, joint research (see also Schlingmann, 2020a). These theoretical thoughts were the basis for the development of the survivor-controlled research subproject SELFORG as part of the joint research project REGROW. The other basis was an observation in the work of self-help groups.

Generalisation of Experiential Knowledge in Self-Help Groups

In institutions like Tauwetter and Wildwasser, long-term observations indicate that an enormous amount of experiential knowledge hides in these self-help groups, especially about violence and ways of dealing with it (Arbeitsgruppe bkA, 2006).[4] Both organisations were founded because of shared experience and observations concerning a deficit in support for CSA survivors. These

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[3] *'Zentrales Merkmal der PGF ist die direkte Beteiligung derMenschen am Forschungsprozess, deren Arbeits-oder Lebensverhältnisse Gegenstand der Forschung sind. Damit ist nicht gemeint, die Menschen als Proband*innen oder Studienteilenehmer*innen in eine Forschung einzubeziehen, sondern als Forschungspartner*innen auf Augenhöhe. Alle Forschungspartner*innen bestimmen gemeinsam die Kernelemente des Forschungsprojekts, von der Auswahl des Forschungsschwerpunkts bis hin zurMethodenauswahl, Datenerhebung und Interpretation der Ergebnisse. Erfahrungen aus dem In- und Ausland zeigen, dass Partizipation in diesem Sinne voraussetzungsreich und deshalb oft schwer zu realisieren ist'* (Wright, 2021, p. 140).

[4] Self-help groups referred to in this article are not 12-step groups but closed self-help groups with open communication.

conclusions are an integral part of self-help groups. The follow-up question was what kind of conclusions, or speaking more broadly, what kind of generalisation was legitimate and why.

Generalisation in self-help groups can have different functions. It can serve the creation of a sense of community or help the individual gain knowledge that leads to an expansion of agency. Of primary relevance for research are those generalisations that serve to gain knowledge. Many paths to these gains in knowledge correspond to methods of knowledge production that are dominant in public discourse and also large parts of academic discourse: The individual experience is summed up, contradictory experience is sorted out as an exception, common experience is searched for – by analogy to the formation of mean values or the highest common denominator and considered valid if applicable to the average or majority of a group. A variance interval of varying width can be used, but there will always be a group of outliers of varying size that falls outside the majority.

This quantitative generalisation method negates the standpoint of the subject and reduces survivors to data suppliers – even when they accumulate and interpret the data.

> Subjects exist in the plural, but not in the average. Individual cases can be put in relation to each other, but not "offset" against each other. It is the individual specifications that are of interest, not the levelling of the average. The individual, subjective cases are not deviations, but the idea of deviation itself deviates from the idea of subjectivity. Accordingly, possibilities for generalization do not lie in central tendencies, but in the elaboration of socially mediated and socially intervening possibilities for action. (Markard, 2000, section 8 subjectivity validity and generalization)[5]

However, qualitative research methods, whether hermeneutic or content analytic, also include interpretation of the collected (interview) data by researchers. Once again, survivors become research objects. This objectification contradicts the generalised interests of survivors: Sexualised violence reduces people to an object or thing, and self-determination and regaining subject status are core elements and goals for working through the experience. The question, therefore, is

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[5] '*Subjekte existieren zwar im Plural, aber nicht im Durchschnitt. Einzelfälle können zueinander ins Verhältnis gesetzt, aber nicht gegeneinander » verrechnet « werden. Es sind die individuellen Spezifikationen, die interessieren, nicht die Nivellierungen des Durchschnitts. Die einzelnen, subjektiven Fälle sind keine Abweichungen, sondern der Gedanke der Abweichung weicht selber ab vom Gedanken der Subjektivität. Verallgemeinerungsmöglichkeiten liegen demnach nicht in zentralen Tendenzen, sondern in der Herausarbeitung gesellschaftlich vermittelter und gesellschaftlich eingreifender Handlungsmöglichkeiten*' (Markard, 2000, Kapitel 8 Subjektivität, Geltung, Verallgemeinerung).

whether and how such a regaining of subject status could take place in the production of more generally valid knowledge (methods of generalisation in the context of research on sexualised violence and their impact on survivors are discussed in Schlingmann, 2020b).

View of Critical Psychology on Self-Help Groups: A Means of Learning and a Research Process

Critical Psychology is a form of psychology that claims explicitly to conduct research from the standpoint of the subject. It emerged from the critique by Holzkamp of 'mainstream psychology' in his book *Foundations of Psychology* (Osterkamp & Schraube, 2013).

Critical Psychology posits that people do not act in a causally conditioned way, but instead are led by reasons.

> Here 'reason' does not mean 'rational' or 'conscious', as can be illustrated by the example of litmus paper: Litmus paper certainly does not turn red or blue consciously, but probably not unconsciously either, but under certain conditions, it changes the question conditionally. This means: unconscious only makes sense in the discourse of reasons.
>
> (Markard, 2007, p. 5)[6]

Reasons for action are by no means always conscious, but they are in principle capable of consciousness. From the subject's standpoint, the individual perceives the circumstances and their meanings and explicates the premises for reasons of action in relationship to their life interests. Generalised statements based on such a 'reason discourse' always have a certain scope of validity that has to be described. Thus, no general and universally valid causal relationships are constructed, but rather the circumstances in which actions appear meaningful and functional to one or more individuals are described (Holzkamp, 2013a).

Self-help groups have the task of enabling participants to improve their agency. They are 'people exploring issues in depth to gain a better understanding of their situation' (Abma et al., 2019, p. 142). What happens in such groups may thus be described as 'expansive' learning (Holzkamp, 2013b, p. 124). By recognising internal reasons for action, it becomes possible to see through personal limitations and reduced interpretations and thus expand one's agency. In this process of 'transcending the immediate' (Holzkamp, 2013a, p. 43), one discovers which actions seem to make sense in which situation and why.

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[6] '*"Begründet" bedeutet hier nicht 'rational' oder 'bewusst', wie sich am Beispiel von Lackmus-Papier veranschaulichen lässt: Lackmus-Papier färbt sich gewiss nicht bewusst rot oder blau, wohl aber auch nicht unbewusst, sondern unter bestimmten Bedingungen, es wechselt die Frage bedingt. Das bedeutet: Unbewusstes macht nur im Begründungsdiskurs Sinn'* (Markard, 2007, p. 5).

An explanation of the subject's reasons for action becomes possible in an ideal situation in a self-help group, considering the social situation and position. But because self-help groups are rarely able to reflect their way of generalisation, this is by no means inevitable and more or less a random by-product. Most participants are not aware of these processes, and it is all too tempting to adopt interpretations offered by society. As a possibility, however, it is inherent in all self-help groups.

Holzkamp (1994) described the coincidence of interpretation or theorising and subjective experience as a possible quality of the 'survivor' discourse of victims of sexualised violence:

> [It is] a constellation … in which the subject of experience potentially coincides with the subject of interpretation, so that the women (thus in the survivor discourse) are able to become subjects of their own discourse. (p. 155)[7]
>
> Women [are] potentially transformed from objects of interpretation by experts (psychologists, psychiatrists, other "professionals") to subjects of theorisation of their own experience of violence. (p. 152)[8]
>
> The generalizations to be gained in this way are thus not frequency generalizations, but – as we put it – "structural generalizations," the gaining of which we have characterised as a subject-science procedure of "self-application" or "self-subsumption." (p. 152)[9]

SELFORG

In 2017, a group of CSA survivors around Tauwetter discussed the idea of applying to the BMBF funding line with a research project. They wanted to achieve two things: The first was to find out whether and how it would be possible to transform the more or less unsystematic generalisation in self-help groups into a research approach for CSA survivors with the help of the ideas of Critical Psychology. The second was to study the multiple ways of processing sexualised

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[7] *'Eine Konstellation, … in welcher das Subjekt der Erfahrung mit dem Subjekt der Interpretation potentiell zusammenfällt, so daß die Frauen (so im Survivor-Diskurs) zu Subjekten ihres eigenen Diskurses zu werden vermögen'* (Holzkamp, 1994, p. 155).

[8] *'Frauen [werden] von Objekten der Interpretation von Experten (Psychologen, Psychiatern, sonstigen » Fachleuten «) potentiell zu Subjekten der Theoretisierung ihrer eigenen Gewalterfahrungen'* (Holzkamp, 1994, p. 152).

[9] *'Die so zu gewinnenden Verallgemeinerungen sind also keine Häufigkeits-Verallgemeinerungen, sondern – wie wir uns ausdrücken – » strukturelle Verallgemeinerungen «, deren Gewinnung wir als subjektwissenschaftliches Verfahren der » Selbstanwendung « oder » Selbstsubsumtion « charakterisiert haben'* (Holzkamp, 1994, p.c152).

violence beyond the clinical settings. These ways – described as self-organised recovery processes – play an important role for quite many CSA survivors.

Through their initiative, the research network REGROW was founded for a joint funding application. The network featured academic research subprojects with varying degrees of participation and a survivor-controlled research subproject,[10] which was titled 'Impact of Self-Organized Ways and Processes for Recovering from Child Sexual Abuse (SELFORG)'.

Unfortunately, the application was rejected. Though the innovative approach and stakeholder participation were explicitly praised, the costs required for this were criticised as too high. 'The budget seems to be too high in relation to the planned sample sizes' (Deutsches Zentrum für Luft-und Raumfahrt, personal communication, 19 March 2017).

A second attempt was made to realise SELFORG in a different setting. Here, too, the project was supported by scientists from a university. However, even before the application was submitted, it turned out that the funding guidelines for health research were not feasible to carry out the kind of survivor-controlled research envisaged. Nevertheless, the many discussions between the scientists and CSA survivors during these processes enabled the development of a research concept.[11]

Design for Self-Organised Research (by Survivors of Sexualised Violence)[12]

Initial Group

As mentioned in self-organised research, the division into researcher and research object is abolished. The question arises: Who initiates the research and who develops the research question? Usually, this is a small number of CSA survivors who have a common interest in finding an answer to a question or problem. They invite others to participate who have the same question. The responsibility for the coordination of the research process from application to publication lies primarily with the initial group, but it is crucial to include as many of the participants as possible. Self-organised research is democratic research.

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[10] The distinction between academic researchers and CSA survivors is not quite correct because there are CSA survivors who have a background in academic research and vice versa. A more precise distinction would be between research projects in which openly acknowledged CSA survivors define the project and those in which academic researchers do so.

[11] The author explicitly thanks the involved scientists who showed a lot of courage and shared a lot of knowledge.

[12] Although this research design was developed for research by CSA survivors, it can easily be adapted to self-organised research by any other group.

Research Groups

The research groups should consist of diverse CSA survivors (backgrounds, gender, etc.). Usually, it is assumed that a group discussion is best conducted with a fairly homogenous group to enable all participants to partake in the discussion (Bortz & Döring, 2006, p. 243). This is because the interpreting researchers later work out different circumstances that lead to different behaviours. If research subjects and research objects coincide, it is useful to bring together different positions in the group discussion so that greater depth through contrast is possible.

One qualification of the participants should be a certain capability to reflect on their experience and relate it to the experience of others. This is best achieved if all participants have partaken in self-help groups before.

It seems advisable to have a certain number of research groups (three or more) to counteract any distortion by dominant spokespersons who may be present in one group. The size of the groups should not exceed five to six people to have enough time to focus on different experiences. On decisions necessary before any group discussion, see Lamnek (1993, p. 146).

Research Group Meetings

The meetings of the research groups should take place at a central location (particularly if participants from different locations are to participate). If possible, meetings should last for a longer period, e.g. three days. Meetings for a longer time at the same place enable better exchange and communication between the participants in the different research groups between single sessions, thus allowing for productive stimulation in the groups.

During the individual sessions of each research group, every group member should have time to relate their experience concerning the research question. The others can discuss the input with the speaker and relate it to their experience and that of the others. It also seems advisable to implement certain rules of discussion to avoid unnecessary injuries. This is comparable to the normal process in a self-help group.

Because the goal of this research is ‘structural generalisation’ (Holzkamp, 1994, p. 152) more than one meeting, most likely three to five, is needed, particularly if an advisory board and the inclusion of ‘outside sources’ (Abma et al., 2019, p. 177; discussed later) are planned. The exact number of meetings depends on the research question and amount of work assigned to the research groups.

A coordinator who has partaken in self-help groups and preferably has experience in self-organised research should be assigned to every research group. The sole task of the coordinator is to ensure a systematic procedure to guarantee a certain quality of research. They are not a researcher who is doing participant observation in field research, but a participant of the research group with a special task.

First Meeting

Training in research methods is an essential part of all kinds of participatory research and even more so for self-organised research. The first meeting necessarily has to focus on introducing the basic categories of Critical Psychology, especially the principles of the reason discourse. Concepts like reasons for action, premises, meaning, etc. need to be understood in relation to one another.

Second, the first meeting has to include a training on how to transcend the immediate by transforming experience clad in everyday terms into scientific categories. Transcending the immediate is facilitated by working in a group of fellow survivors. They look at the actions of the focal participant from their own subjective standpoint, which enables the focal participant to see different aspects. The alternation between individual introspection and reflection in the group enables the individual to look behind the scenes. This was first practiced in a research project in 1984 about becoming a subject in childhood (see Bader et al., 1984; Holzkamp et al., 1985; Markard, 1985). They developed the method to write diaries that were discussed with two advisors and the whole research group.

Holzkamp used the term *social self-understanding* to describe the research process in which researchers and the objects of research are the same people. He talked about a process of successive transformation from pretheoretical discussions to scientific conceptualisation:

> One talks, in the end, about the same problem as at the beginning, but on a higher level of self-reflection and object-relatedness. This process gains its depth and stringency from the gradual issue-related integration of the pertinent basic subject science concepts discussed above. In this way, their relations to the overall concept are progressively established through which the initially noncommittal talks gain scientific stringency. This development is tantamount to changing from pre-theoretical discussions to theoretically conceptualising the topic at issue.
>
> (Holzkamp, 2013c, p. 338)[13]

In other word, the training can enable the research groups, which initially will be more of a prolonged self-help group, to increasingly become scientifically working research groups.

This first meeting also allows the formation of the research groups and gives the participants a chance to get to know one another. This is inevitable, because it is likely that most of them don't know one another and they will be working together on a topic that usually is regarded as very private. Enough room is needed to build up trust among the participants.

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[13] Original in English.

Following Meetings

The actual research begins with detailed reports from the participants about their experience regarding the research question. The other group members have the task to encourage the speakers and ask them why they acted the way they did. This can easily be misunderstood as a rejection or questioning of their perception. That makes it indispensable that the principles of the reason discourse (see previous discussion) are explained with ample time in the first meeting. This session is audiotaped and transcribed. Based on the transcription, each person writes a summary of their experience and explanations for their behaviour.

In the next sessions, the respective reasons for action are worked out from these summaries. From these reasons for action, the premises are explicated and jointly questioned to reveal abbreviations and interpretations. On this basis, the conditions and meanings underlying the premises are elaborated. The precise description of these conditions and meanings determines the respective scope of validity of the results. Thus statements are made under what circumstances actions appear subjectively functional and are aspired.

The research groups present their results to the other groups and discuss them with them. Seemingly contradictory results suggest different scopes of validity, i.e. they force a specification of the scope. Afterwards, the research groups meet on their own again and revise their results in the light of the results of the others.

A written report of their research and results is the last task of the different research groups. The responsibility for organising a joint publication that compiles the results lies with the initial group.

Possible Additional Improvements

Members of the International Collaboration for Participatory Health Research have stated in their book *Participatory Research for Health and Social Well-Being* that in participatory research, it is necessary ‘to be open to results that may not be, what we expected or hoped for’ (Abma et al., 2019, p. 175). This is equally true for self-organised research. Among others, they propose ‘comparing to outside sources’ (p. 176) and ‘consulting with critical friends’ (p. 177), two options that are easily adaptable for self-organised research.

Consulting With Critical Friends: A Scientific Advisory Board

An interdisciplinary advisory board of scientists with profound experience in research concerning sexualised violence, Critical Psychology and survivor-controlled research can be formed to advise the CSA survivor groups. The intermediate results of the research groups can be presented to this board, which could comment on the results and give suggestions. The comments and suggestions will be incorporated in the next research group meetings.

Comparing to Outside Sources: Research Databases, Online Surveys and Literature Review

The easiest step to including external material is to investigate whether there are results from any other research projects with a similar research question. Considering how often CSA survivors think that research does not really help them with their problems (Schlingmann, 2016), it may not seem very likely, but it is still a possible source.

Online surveys are in no way participatory or self-organised research, but they may be a form of subject science research. The fact that online samples usually are convenience samples and not representative is irrelevant for subject science because it aims for another form of generalisation. Online surveys are a fairly easily accessible tool, and it seems worth a try to ask interested people open questions in the language of the reason discourse. It seems advisable to look for a cooperating university or research institute to start such complementary research, which would be necessary to evaluate whether subject science online surveys are possible and under what circumstances.

CSA survivors in self-help groups, political initiatives, counselling centres and as activists produce a huge amount of grey literature. In literature reviews, this literature usually is not taken into account. Considering that this literature is based on personal experience of CSA survivors, it is likely that a review of the grey literature will enrich the research.

Conclusions

Although the SELFORG research was not funded, developing it through cooperation between scientists and CSA survivors was a very fruitful process. If such self-organised research were to be conducted, important impulses would emanate from it for research on sexualised violence. In such a way, results can be achieved that could not otherwise be obtained. Moreover, such research would be a breakthrough in subject science research in general.

Such research could also have considerable effects beyond the immediate scientific interest: Survivors of sexualised violence could break out of their socially ascribed role as eternal victims and provide important contributions to research on sexualised violence. It would be difficult to achieve a greater empowering effect with this breadth and radiance in any other way.

Such models for subject science knowledge production could also enable CSA survivors to develop new models of coping with their experience in self-help groups. From thereon, it might be possible to develop methods that could allow children and adolescents to shorten the process of working through the violence in the long run. Both aspects are especially important for those who do not have access to other support.

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Chapter 16

Giving Voice to the Survivors of Childhood Institutional Abuse

Petra Filistrucchi, Patrizia Bucarelli, Giuseppe Aversa and Donata Bianchi

Abstract

This chapter focuses on ways of giving voice to the survivors of institutional abuse and how their contribution can be capitalised in raising community awareness of this phenomenon. The collection of testimonies demonstrates that institutional abuse is a common and widespread phenomenon that in most cases remains unrevealed throughout the life course. The participatory research process we describe is part of an important social and clinical intervention developed in the framework of two projects. The chapter illustrates outputs and outcomes related to disclosure of institutional abuse and its long-term consequences, as well as the meaning and implications of collective trauma. Results confirm the need to promote the voice of survivors to build a new professional and community culture and sensitisation towards children's right to be heard as an essential instrument to prevent and detect institutional ill treatment. Participatory processes can overcome the resistance of individuals, professional communities and politicians to recognising the phenomenon, emphasising institutional responsibilities and the specific effects of a serious form of maltreatment that requires extraordinary and specific interventions in terms of intensity and flexibility. This chapter describes a fieldwork and research experience made possible thanks to a strong alliance with survivors who engaged in a process of reflection and theoretical elaboration that generated both social and clinical impacts.

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Keywords: Child sexual abuse; institutional abuse; social problems; healing; restorative justice; out of home childcare

Introduction

Institutional abuse of children was first conceptualised in the 1980s, when a public enquiry was launched to focus on institutional abuse as a named social problem in the United States (Daly, 2014a; U.S. Department of Justice, 1979). Since 2000, many more national enquiries have been launched or completed in Australia, Belgium, Canada, Denmark, England, Wales, Finland, Germany, Iceland, Italy and many other countries (Roth et al., 2019). In addition, in 2012 and 2013, two large enquiries were launched in Northern Ireland and Australia (Wright, 2017; Wright et al., 2017).

The book *The Country of Celestini* (Serra & Santanera, 1973) described many cases of violence in orphanages in Italy and identified the relevance of external social and institutional settings, in which such violence was somehow facilitated by neglect of service interventions, social inequalities in the institutions and the fact that child victims had a lower social status.

Institutional abuse refers to 'abuse occurring against children living in institutions or in out-of-home care (foster care and foster homes)' (Daly, 2014a, p. 6). It has no single cause, and it is not only the responsibility of the direct perpetrator; it is often the result of the entire system, which colludes, covers, justifies and sometimes motivates violence against children. Gil (1982) identified three distinct forms of institutional child abuse: (1) direct institutional maltreatment: i.e. physical, sexual or emotional abuse committed by individuals directly responsible for the child's care; (2) procedural maltreatment, i.e. programme abuse that occurs when programmes operate below acceptable standards or rely on aggressive or unacceptable methods to control the child's behaviour and (3) system maltreatment, i.e. system abuse that is not committed by a single individual or agency but occurs when the childcare system is stretched beyond its limits and is also related to inadequate control by the agencies responsible for the care of children.

Survivors involved in this participatory research process shared experiences of abuse related to all three categories. They discussed the implications of being victims of violence in places that should have protected them. They faced the researchers with the dramatic powerlessness of being victimised by authoritative and affectionately significant adults in institutions with guardianship and protective responsibilities. The voice of survivors makes clear how institutional abuse is typically an ongoing process rather than an isolated incident in which an abuse of power and breach of trust occurs and which may involve severe physical, sexual or emotional maltreatment.

The survivors of institutional abuse involved in the framework of Project Oltre and the European project Support to Adult Survivors of Child Abuse in Institutional Settings (SASCA) clearly identified institutional abuse as an important social problem that has long been ignored, denied or minimised. Adults who spent their childhoods in care have come forward through public enquiries, truth commissions and the media to allege physical, emotional and sexual abuse and neglect while in the care of governments, nongovernmental agencies, religious institutions and out-of-home care programmes. Their courage has forced society to face painful realities about trusted community leaders, established organisations and cherished institutions. Slowly, international concern has emerged about the trauma they endured and its significant lifelong impacts. Society has been – and still is – slow to acknowledge such acts of abuse (Wolfe et al., 2001).

Participatory Research With Adult Survivors of Institutional Abuse

This participatory research with adult survivors was developed by Associazione Artemisia using the framework of Project Oltre, which was implemented with the support of Regione Toscana to respond to the needs of the adult survivors to the violence suffered in the Forteto, and through the European SASCA Project. Forteto was a residential childcare community, close to Florence (SASCA, 2018). Hundreds of victims were directly or indirectly involved in this case of very serious institutional abuse: more than 80 out-of-home children and adolescents, their original families and about 60 adults with disabilities. The maltreating nature of the life rules adopted in 'Il Forteto' is proved by two final judgements of the Court of Florence of 1985 and 2020, which ascertained the repeated and systematic damaging acts that violated the fundamental human rights.

Both projects addressed events in which an institutional system ignored what happened, colluded or actively participated: Il Forteto and I Celestini in Italy (and single experiences of mistreatment not included in this group), the Magdalene Laundries in Ireland and the abuses in institutes in Greece and Romania.

In addressing this issue, the SASCA Project adopted the perspective of the victims, former boys and girls. The participatory research in SASCA involved 101 survivors of abuse and maltreatment in institutions. The data were collected by a self-administrated questionnaire and an interview. The questionnaire gathered demographic data and used scales to measure the physical effects of the trauma. We recruited a sample based on the snowball method, mainly through contact with associations and informal groups of survivors, contact with local social services and advertisements. Institutional abuse was also analysed through a survey with 390 social and health workers and 40 judges and other legal operators at a European level. This chapter mainly focuses on the results of the interviews with 33 survivors of child protection institutions in Italy, as the first fundamental step in the process underway in our country to promote the leading role and participation of survivors of institutional abuses (Bucarelli & Filistrucchi, 2019) in a path of regaining awareness and promote change in the civic, professional and political community on the issue.

The interviews were realised with the following objectives: to (1) understand and address the problem of child abuse in institutional settings, particularly in residential care, from the perspective of adult survivors; (2) understand the long-term effects of such events; (3) understand how and if the survivors of these crimes may find protection and compensation in the existing legal framework and (4) understand how their experience may enlighten prevention strategies for the protection of children in residential care today.

The interviews with adult survivors gave voice to their stories and pain, and by listening to their opinions, we confirmed the need to identify key characteristics of possible intervention and prevention efforts.

Brief Review of Characteristics of Survivors Interviewed in Italy

Most of these interviews occurred with the survivors of Il Forteto and I Celestini; however, the researchers also collected other experiences of institutional maltreatment that mainly involved religious institutions.

The respondents had an average age of 42 years, with a range from 24 to 65. Two-thirds were men. They entered into the institutional system when they were 8 years old on average, Most of them were forgotten and physically and psychologically segregated in the institution for many years; in the case of Il Forteto, 36% of the respondents remained there for more than 15 years.

They suffered a wide range of violence: serious relational and material negligence, physical and psychological abuse, exploitation in work activities, sexual violence and institutional neglect by social services after the placement of the children in the institutions. The responsibility of the system clearly emerged from the answers of some interviewees regarding to whom they attributed the greatest responsibility. Next to the direct perpetrators of the abuses, the survivors recognised both justice operators and social services, which should have monitored and supported them as children, as being responsible for the abuses they suffered.

In most cases, the violence they suffered was not reported when it occurred; only seven respondents disclosed the abuses while children. Some realised only many years later that what happened to them was wrong and that they were victims of violence; many were afraid of the consequences and not being believed and many others were not helped to understand that they could report the abuse. Awareness of the severity of the suffered abuses, therefore, is often a slow and difficult conquest in adulthood. For this reason, most of the survivors declared themselves against prescription of childhood abuses, considered a legal measure that makes it impossible to seek justice.

Lessons Learnt on Child Abuse and Neglect in Out-of-Home Care From the Perspectives of Survivors: Disclosure, Responsibility and Prevention

The participatory process allowed a focus on issues that sometimes are already known to professionals but lack the complexity that emerges from the voices of people directly involved. Sharing the burden of building a common understanding represents, for all the actors involved (survivors, researchers and professionals), an extraordinary opportunity to gain access to new insights and information on the dynamics and impact of institutional maltreatment.

Disclosure

Most survivors disclosed their story many years after the abuse had taken place. The interviews confirmed the burden of disclosure; being abused in institutional settings is a severe and complex experience. How can they talk – and to whom – about the maltreatment and abuse they suffered in a place that should have protected and defended them? They had to face confusing, contradictory and destabilising messages. There was no adult to whom they could turn. No one could see or understand what was happening to them.

And the backdrop of all this was a paradoxical communication, on the verge of perversion, as if children were told: 'I move you away from your family – with all that I know it involves – to protect you, and to do so, I put you in a new and often more serious maltreatment context'.

The child victims could only think that what happened was right, that it made sense that no one intervened to protect them. The thought of not being worthy of anything else, of not being worthy of love, was combined with the conviction that what happened was deserved.

> First, I've been beaten by my parents, and then by the community leader. … I was a little bastard.
>
> (SASCA, 2019, p. 13)

The frequent visits of outsiders never noticed any sign of abuse in these institutions. Thus, they contributed to the good fame and credit of the organisations and strengthened the pervasive experience of children's helplessness and perception of not being credible.

> I always hoped someone would notice something. … There were so many people coming to Il Forteto, I always hoped.
>
> (SASCA, 2019, p. 13)

The disclosure of violence didn't happen because they were threatened, ashamed or didn't know to whom to disclose, or if it happened, children rarely were listened to or their situation became even worse after they complained. Many complaints of child victims of institutional abuse were not formally reported and as such, no measures were taken to address the situation, either because there was a conspiracy to keep allegations quiet or a ready acceptance of the denial by the alleged perpetrator.

> One day, this boy in the classroom started saying what this priest was doing, and the teacher, instead of investigating if the problem existed, turned off the discussion by saying, "But what do you say?

> Do you think these are speeches to do?" And at that moment I thought, "Come on, now this thing will come out and finally I expose myself," but I saw that instead the teacher had turned off everything and I saw the only hope I had disappeared. The teacher silenced him right away. What the fuck – the only person you talk to makes you shut up? Who do I go to?
>
> (SASCA, 2019, p. 13)

With respect to the enormous difficulty of disclosing the violence that children suffered or witnessed every day, the survivors clearly told us about the powerful experiences that have prevented their revelation for years, for decades: fear, shame, sense of guilt and impotence.

They experienced shame and guilt, very often, about not being able to react. Disclosing also meant exposing them to the risk of 'being pitied or making pity'. The words of these survivors indicated the depth of their sense of loneliness and insecurity, how total the loss of their trust in relationships and how pervasive the intensity of their anger.

More generally, for almost all interviewees, disclosure had been a long and tiring process that occurred almost always when they were out of the community – this means in adulthood. An important incentive was their relationship with peers; some survivors described how the comparison with peers, who shared the same experience, from a certain point onward was very important, not only to receive the support they needed to survive but also to become aware and gain courage.

Responsibility

In the institutional maltreatment of children in care, the issue of responsibilities, particularly that of prevention, is central.

Most respondents identified the great responsibilities of those who, in their childhood, first removed them from their family of origin, then placed and abandoned them in the residential care: These were social workers and judges.

The theme of responsibilities aroused in the survivors particularly intense waves of anger and sometimes distrust. Other feelings that emerged in the interviews were the sense of collusion, superficiality and indifference on the part of the child protection system, which did not want to see and understand their suffering.

> I do not even feel anger. I feel disgust, because I think they were washing their hands and not giving a shit about each other's ass. A negligence of the magistrates and of the social services that followed the minors in custody at Il Forteto, treated so lightly. ... They made decisions based on friendship. These were the

> mistakes that led them, the members of Il Forteto, to be so powerful.
>
> (SASCA, 2019, p. 14)

> Social workers … they took us, they put us there. … We were granted as if we were goods to be unloaded from a truck.
>
> (SASCA, 2019, p. 14)

The theme of collusion recurred dramatically in the interviews. This aspect was present even among survivors from religious institutes; they repeatedly underlined the precise and conscious will of the church to conceal the facts, and it seems that the repeated and late scandals relating to sexual abuse in ecclesiastical circles have received an objective confirmation. Many people told us about having suffered threats even years later.

> Why didn't you say it before?" Look at the facts of today and give yourself an answer: Even now, many do not believe us. They continue to defend. … Imagine before. Too many hook-ups.
>
> (SASCA, 2019, p. 14)

In one interview, the respondent explicitly stated that children who have had such experiences should be qualified as 'system victims' (SASCA, 2019, p. 15).

Prevention

The difficulty of recognising and working constructively on professional responsibilities is inevitably a major limitation to prevention.

These survivors were very proactive in indicating possible strategies and tools for the prevention of institutional maltreatment. They agreed about the continuous relationship with an external social worker, educator and psychologist as a crucial factor to prevent maltreatment. The perception of the survivors is that once the placement has taken place, social services view the 'problem' as solved and the social worker does not care about how protection is implemented and the well-being of the child. In their stories, the social workers disappeared or sometimes there was a continuous turnover of them, one after the other.

Another recurrent and central aspect is that meetings with social workers in their office or residential care never had the character of confidentiality because a professional belonging to the community was always present. This also happened in the rarer but no less significant cases in which the victim had been involved in counselling, psychological support, listening with juvenile judges or more regular visits with social workers.

The most important protective factors related to the risk of institutional maltreatment seem to be the personalisation of the intervention, not delegating a periodic assessment of the situation and the existence of a real relationship between those who protect and those who must be protected. For this reason, regular and continuous individual meetings with their social worker or other professional figures outside the community, such as a doctor or psychologist, are perceived as necessary protective factors. Nevertheless, monitoring of the process of bringing up children in institutional care can fulfil its objective – of surveying the safety and well-being of children – only if it surpasses the limits of bureaucratic routines.

Survivors almost always described not having felt seen or heard. Prevention relies on the ability to construct interventions in which children are protagonists and not only recipients, and the possibility that children are more active and aware of their rights through adequate information and authentic listening.

> They should use different methods when they do community check-ups. Often when they come, they don't even talk to the children. They check if there's food in the fridge, if there are adequate clothes … and that's all. I remember the questions: "So, how was your day? Are you fine, yes? Great, then." My social worker never asked me how I felt or asked me to really say something. … He should have tried to make me talk, but he was not curious, not even a little!
>
> (SASCA, 2019, p. 16)

In some interviews, participants explicitly referenced the spread of burnout among social workers, indicating insufficient training and professionalism.

The need for greater social and economic recognition of these professions was underlined, as was a greater awareness of their great responsibility and power to affect – positively and negatively – people's lives. Among the most effective prevention tools are adequate training, constant updating, improved supervision and the opportunity to collaborate in a work team. In this regard, it is important to underline that in December 2021, under the proposal of the Ministry of Welfare, the Italian Parliament adopted an act that introduces and finances the supervision of social workers as an obligation.

Almost all survivors recognised the need to have adequate time to devote to children in protection. Instead, most social workers find themselves working in solitude, with a disproportionate workload, constrained to facing continuous emergencies in a situation of progressive contraction of resources and tools at their disposal. All these elements, together with the structural deficiency of the service system, constitute a fertile ground for the occurrence of professional mistakes, for the repetition of similar stories.

Restorative Value and Power of Taking and Giving Voice

Being abused in institutional settings that were supposed to provide protection causes a sense of 'institutional betrayal' (Higgins, 2001; Morrison, 2005; Parkinson et al., 2009; Smith & Freyd, 2013), linked to the complicity of institutions in allowing and not detecting abuse and making the victim accessible to the abuser. This amplifies the psychological and psychosocial impact on survivors and often finds yet another confirmation when the surviving child, adolescent or adult tries to disclose what happens.

At a broader systemic level, institutional abuse involves the failure of the system that is supposed to protect children (Bianchi et al., 2018). The abuse suffered by survivors could have been prevented if there were adequate legislation for the protection of children's rights, if supported by appropriate child protection policies and practices, if each social worker had correctly exercised their role and responsibilities, if the context were not influenced by the prestigious reputation of the institution in which the abuse occurred, etc. (Aversa et al., 2021). From the research available and these interviews, it seems particularly damaging to know that what was needed and could have been done to prevent abuse was not realised due to negligence (Smith & Freyd, 2013).

> It could have been different ... if only one had gotten in the way. And instead ... all these "I don't know," these slight – these "I don't remember" to us, they ruined our lives.
>
> (Survivor, personal communication, 2020)

Consequences of Institutional Abuse as Perceived by Survivors

As the persecutor does with the victim, in institutional abuse, the institution confirms the victim's feeling of being invisible. This institutional betrayal partly explains the more severe outcomes associated with trauma experienced in institutional settings. In many respects, victims of institutional abuse have to deal with the impact of the abuse and the betrayal of the social institution in which the abuse occurred. The result is a deep and powerful experience of betrayal and helplessness, which adds to the deep-rooted belief of an irreversible malfunction of their self and the world.

The scientific literature unanimously describes institutional abuse as more serious in its impact on victims than other forms of child abuse (Magalhães et al., 2009). The effects of neglect and abuse leading to protection and removal from the family of origin cumulate with those of institutional abuse and take on more severe characteristics. Research (Balkemore et al., 2017; Carr et al., 2010; Magalhães et al., 2009) has shown evidence of insecure and disorganised attachment in survivors of institutional abuse. Survivors of institutional abuse have described a global loss of trust and fear of intimacy, shame, guilt and humiliation, fear of or disrespect for authority, avoidance of reminders of their abusive experience and vicarious trauma. Survivors are confronted with coping with not only the devastating impact of the abuse but also the betrayal by the valued social institution and loss or impairment of its role in their lives. Institutional betrayal is defined as the wrongdoings perpetrated by an institution on which individuals depended, including failure to prevent or respond supportively to wrongdoings by individuals (e.g. sexual assault) committed in the context of the institution (Gobin & Freyd, 2009).

Lessons Learnt From the Perspective of Child Abuse and Neglect

The results of the survey indicate the need to move along two complementary dimensions, one individual and another collective or communal. Damage caused by institutional maltreatment cannot be elaborated and repaired exclusively by victims on individual paths. Victims of institutional maltreatment are also, inevitably, victims of the state, which placed them in institutions that betrayed their original mandate and which the state did not adequately supervise.

Leaving aside in this description the specificity of the healing process and therapeutic elaboration, it is important to consider the reparative value of 'giving a voice' for the survivors as an experience of reassumption of power and credibility and the construction of an opportunity to be heard in the professional, social and political context.

No less important is the transformative value of the process of 'giving voice and listening' that also involves institutions and professionals. In dealing with institutional abuse, all survivors, institutions and legal and social operators are seized by shame, helplessness and despair that sustains the belief that tomorrow will be identical to today.

Giving voice to survivors shows that looking, recognising, questioning, regaining awareness and going through helplessness and shame is the only way for all – survivors and social workers – to recover the power of change. Acknowledging that 'it could have gone differently' is very painful, yet that means it can go differently.

Developing a voice to disclose, tell and denounce, in alliance with professionals of the system to be changed, is a different level of the healing path, in which the individual story becomes part of a wider strategy for change and prevention. It is a more challenging step, different from courageous complaints or survivors' participation in TV broadcasts, although they are important in the initial phase of disclosure for counteracting the negation and collective removal. These actions have often exposed survivors to attacks, blame and discredit for broken silence because when someone becomes a bearer of the testimony of crime, others share the responsibility of restoring justice (Herman, 1997).

Much of the general public's current understanding of child abuse that occurs in institutions and organisations is derived from high-profile media reports of investigations, arrests and court outcomes. The public often is presented with an incomplete picture of the circumstances surrounding the institutional abuse reported. The result can be a backlash towards survivors, who may be seen as responsible for the troubles experienced by the institutions, rather than the institutions or perpetrators being held accountable (Daly, 2014b; Wolfe et al., 2001). They become traumatised people who have not conquered their demons, who make demands for money because they are unable to build a life for themselves (Aversa et al., 2021).

The path of participation that we offered has given the possibility of creating connections between survivors and the system of services, mainly social workers. It opens an alliance that leaves room for testimony and recognises the role of the interlocutor, forcing the professional to engage in authentic listening. It is a new alliance, a pact that recognises differences but shares the path and goal: that suffering can serve someone and prevention is possible.

Conclusions From the Perspective of Participatory Research

In the framework of this participatory research, the interview and its many questions have often been the first opportunity for survivors to experience being credible interlocutors, carriers of a practical and subjective competence that is necessary to understand what happened and draw new horizons. It is the first step of the possibility of building participation, trust and protagonism with the world of professionals (Herman, 1997).

With SASCA, the parallel journey of a scientific–professional community has started, too. The answers of survivors, indicating the gravity of institutional abuse, forced professionals to question their strategies and efficiency in addressing children who experienced abuse.

Sharing between professionals and survivors raised awareness of the phenomenon and its dynamics, expanding the possibility for breaking the silence around institutional abuse. The different settings and formats alternated among focus groups, conferences, training for social workers and consultation tables with professional bodies, allowing us to jointly face this issue, give voice to survivors and strengthen the capacity of professionals to listen and work together.

The valorisation of survivors as experts by experience and involvement, when possible, in the group has favoured the possibility of reasoning together about their experience and stimulated the passage from individual experience to the acquisition of an awareness of their transformative power as experts who can assume an active role as builders of collective knowledge, as bearers of not only suffering but also transformation and improvement in a professional community that can hopefully learn to listen and question itself. Survivors are no longer a social problem to be addressed, but a resource to be valorised. In this framework, the Committee of Children Abandoned at Forteto by the State took action. These survivors are among the more than 90 children, boys and girls, who have been placed in the Il Forteto Children's Home by the juvenile court or social services during more than three decades. Their objective, above all, is to transform their lived experience into the starting point for reflections, doubts and changes, including legislative ones. This expresses the desire to bring the attention of the state back to the protection of children, who absolutely need more resources than they currently have (Aversa, 2020).

They are now an actor in collaboration with institutions to transform pain into hope. They are recognised as a stakeholder. Members of the committee were involved in a focus group aimed at collecting information and proposals on the experience of being removed for a periodic report to the Parliament on the implementation of laws and norms related to the protection of children in need.

The integration between competence by experience and formal competence is also valuable with respect to the information and training activities of professionals. The 'experts of experience' help professionals recognise their enormous professional responsibility and impact on the life trajectories of victims.

Education and training need to be directed at institutions (e.g. staff, volunteers, board members) and community professionals who provide services to survivors. Many survivors describe the legacy of their abuse being compounded by lack of intervention and prevention programmes, despite their efforts to break the silence. Listening to survivors' voices can be a way to enter the complexity and pervasiveness of institutional mistreatment and understand how much we have to learn to ensure effective protection of boys and girls when they are in conditions of vulnerability due to the fragility of their families of origin. This may allow a culture characterised by blame and moralistic judgement to be overthrown, leading to the development of a generative approach (Bertotti, 2020).

The effort to view what happened from a perspective of prevention and generous attention to children who are today at the centre of the removal and protection measures motivates enhancement of the protagonism and participation of survivors in contexts of reflection on professional practices. The search for connections between past and present, for example, creates a fertile link between these survivors and the experiences of the Care Leavers, which in the Italian and European network have created a movement capable of influencing public policies and advocacy.

Last, as the motto says, 'the union makes strength'; thanks to shared work in Italy and at the European level, the experiences of these survivors led to a formal declaration on this issue by the Committee of the Parties to the Council of Europe Convention on the Protection of Children Against Sexual Exploitation and Sexual Abuse (Council of Europe, 2007), which has recognised the institutional abuse that takes place in residential communities, particularly violence and sexual exploitation (Lanzarote Lanzarone Committee, 2019). In particular, the Lanzarote Committee asked state parties to ensure that all types of out-of-home care settings feature comprehensive screening procedures for all people taking care of children; specific measures to prevent abuse of children due to their increased vulnerability and dependence; adequate mechanisms for supporting children to disclose any sexual violence; protocols to ensure that in the event of disclosure, effective follow-up is given in terms of assistance to the alleged victims and investigation of the alleged offences by the appropriate authorities; clear procedures to allow for the possibility of removing the alleged perpetrator from the out-of-home care setting at the onset of the investigation; effective monitoring of practices and standards to prevent and combat child sexual abuse; provision of long-term assistance in terms of medical, psychological and social support and legal aid and compensation to victims of sexual abuse in out-of-home care settings; assurances that professionals working in the public, private or voluntary sectors who either commit or fail to report offences occurring in out-of-home care settings are held liable; and guarantees that legal professionals who fail to protect children in their care are held liable.

At the same time in Italy, survivors and experts continue on a path that, starting from the story of Il Forteto, which is now the subject of a parliamentary commission, overcomes the specificity of and identification with the Forteto affair to strengthen and make concrete the possibility of influencing the community (political agenda, professional world, etc.) with a theme as uncomfortable as that of institutional mistreatment.

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