Participation of children and young people in research

Opportunities and challenges

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Ágrip

Markmið þessarar doktorsrannsóknar er að auka þekkingu og skilning á því hvernig hægt er að styðja börn og ungmenni (hér eftir börn) til þátttöku í rannsóknum sem varða þau sjálf. Sérstök áhersla er lögð á að varpa ljósi á þær áskoranir sem rannsakendur standa frammi fyrir í vinnu með börnum og hvernig þær tengjast aðferðum, nálgun og réttindum barna til þátttöku í umræðu og ákvarðanatöku.

Spurt er: Hvaða siðferðilegu og aðferðafræðilegu áskoranir þurfa rannsakendur að takast á við til að fá aðstoð hliðvarða við aðgengi að börnum í félagslegum rannsóknum? Hvernig skilur fagfólk í barnaverndarþjónustu hagnýtar afleiðingar þátttöku barna í rannsóknum? Hvernig má aðlaga rannsóknaraðferðir til að yfirstíga aðferðafræðilega erfiðleika vegna þátttöku barna?

Rannsóknin byggir á sjónarhorni gagnrýnnar hugsmíðahyggju og bernskufræða, þar sem litið er á börn sem virka þátttakendur í að móta félagslegt umhverfi sitt og þar með mikilvæga samstarfsaðila í rannsóknum. Fjallað er um aðferðir sem hafa reynst árangursríkar við að draga fram reynslu og sjónarhorn barna, sérstaklega þeirra sem búa við flóknar félagslegar aðstæður.

Rannsóknin samanstendur af fjórum fræðigreinum sem hver og ein varpar ljósi á ólíka þætti þátttöku barna í rannsóknum. Fyrsta greinin fjallar um stöðu þekkingar á áskorunum rannsakenda við að fá börn til þátttöku og samskipti við hliðverði. Önnur greinin lýsir reynslu rannsakenda af því að sækja um aðstoð við aðgengi að börnum sem búa við félagslega erfiðleika og tengslum þeirra við hliðverði. Þriðja greinin fjallar um viðhorf fagfólks í barnaverndarþjónustu til þátttöku barna og hlutverks hliðvarða. Fjórða greinin skoðar notkun listrænna og skapandi aðferða til að styðja börn við að tjá sig um viðkvæm málefni.

Niðurstöðurnar benda til þess að ferli umsókna um aðgengi að börnum sem búa við félagslega erfiðar aðstæður sé flókið og tímafrekt. Umsóknir fara í gegnum stigveldi formlegra og óformlegra hliðvarða sem eiga að verja rétt barna til þátttöku og verndar. Fagfólk í hlutverki hliðvarða þarf að leggja tíma og orku í að meta umsóknir rannsakenda og ef umsóknin hlýtur brautargengi að leita eftir hugsanlegum þátttakendum. Fram komu efasemdir um að fagfólk sem væri störfum hlaðið, hefðu skyldu til eða ættu að sinna hliðvarðarhlutverki því sú staða gæti haft skaðleg áhrif á oft viðkvæmt samband þeirra við notendur. Fagfólk telur mikilvægt ef þetta eigi að vera þeirra hlutverk þurfi rannsakendur að leggi sig fram við að vera í samvinnu við þau um eðli og umfang rannsókna. Rannsakendur þurfi að vanda til verka við umsóknir, oft vanti upplýsingar um hæfni rannsakenda í vinnu með börnum og rökstuðning fyrir því

að nauðsynlegt sé að tala við börn frekar en fullorðna með svipaða reynslu. Hluti fagfólksins taldi ekki við hæfi að biðja börn í viðkvæmri stöðu um að ræða stöðu sína við rannsakanda, málefni sem þau kunni að hafa takmarkaðan skilning á.

Rannsakendur túlka hins vegar langan umsóknarferil, tregðu og lítinn áhuga fagfólks á rannsóknum og sem merki um ríkjandi verndarhyggju þegar börn eiga í hlut.

Til að efla beina þátttöku barna þurfa rannsakendur að leggja áherslu á vandaðan undirbúning og faglega framsetningu umsókna og rannsóknaráætlana. Nauðsynlegt er að byggja upp traust og tengsl við hliðverði, sýna fram á hvernig tryggja megi öryggi barna og útskýra hagnýtt gildi rannsóknarinnar. Þá þurfa rannsakendur að gera grein fyrir hæfni sinni og leikni við vinnu með börnum og við að beita skapandi aðferðum sem stuðla geti að merkingarbærri þátttöku.

Til að standa vörð um réttindi barna þarf að efla hæfni rannsakenda í vinnu með börnum og auka þekkingu fagfólks á bernskufræðum, réttindum barna og merkingarbærri þátttöku. Slík þekking getur dregið úr ríkjandi verndarhyggju og vantrausti gagnvart rannsakendum, sem annars hamlar raunverulegum möguleikum barna til að hafa áhrif á eigið líf og aðstæður með þátttöku í rannsóknum.

Lykilorð:

Barn – Hliðvörður – Réttindi – Sköpun – Vernd – Þátttaka.

Abstract

The aim of this doctoral thesis is to increase knowledge and understanding of how children and young people (CYP) can be supported to participate in social research on issues that concern them. Particular emphasis is placed on highlighting the challenges researchers face when seeking access to CYP, and how these challenges relate to methods, approaches and children's rights to participate in discussions and decisions concerning their own lives and circumstances. The study addresses the following questions: What ethical and methodological challenges do researchers need to overcome in order to obtain support of gatekeepers to gain access to CYP for participation in social research? How do practitioners in child protection services understand the practical implications of CYP's participation in social research? How can research methods be adapted to overcome the challenges of involving CYP in research?

The study is grounded in a perspective informed by critical social constructionism and childhood studies, in which CYP are regarded as key social actors who shape their environments. Accordingly, their participation is considered essential in research. The study discusses methods that have proven useful in eliciting CYP's experiences and perspectives, particularly in sensitive contexts.

To gain insight into the subject, the study examines the experiences and perspectives of child protection practitioners who serve as gatekeepers when researchers seek access to CYP, as well as the experiences of researchers who have conducted research involving CYP. It also draws on existing data to reflect the perspectives of parents and CYP regarding participation in research and data from CYP about the usefulness of creative methods when working with CYP.

The study is based on four peer-reviewed papers. The first paper explores the current state of knowledge regarding the challenges faced by researchers in this field. The second paper examines researchers' experiences in gaining access to CYP who receive support due to difficult life circumstances, and their interactions with formal and informal gatekeepers. The third paper focuses on practitioners working with CYP in child protection services and their perspectives on supporting researchers in gaining access. Lastly, the fourth paper discusses how creative and artistic methods can support CYP in discussing sensitive topics.

The findings reveal a complex and challenging process for researchers seeking access to CYP in vulnerable situations for research participation. Applications for access must navigate a hierarchy of formal and informal gatekeepers who are responsible for

safeguarding children's rights to protection and participation. Challenges are evident in the lengthy approval processes, often resulting in extended delays or rejections, frequently without clear justification.

Researchers depend on the goodwill of practitioners occupying key positions within this hierarchy, each of whom must dedicate time and energy to determine whether or not to support access to the target group. Researchers associate these delays and reluctance with a perceived lack of interest in research among practitioners and with assumptions about children's competencies, both of which significantly influence whether applications for access are considered or granted.

Practitioners working in child protection, who act as gatekeepers, report limited time for engaging with research-related tasks and criticise researchers for submitting unclear research plans. These plans often lack sufficient explanation of researchers' competence in working with CYP, strategies to ensure child safety and justifications for involving CYP directly rather than relying on adults as informants. Frequently, the plans also fail to adequately describe researchers' prior experience or use of appropriate methods. Many practitioners consider it inappropriate to burden CYP in vulnerable circumstances by asking them to participate in research, particularly when discussing matters of which they may have limited understanding. According to practitioners, researchers should avoid compromising CYP's safety through participation and instead focus on utilising existing data collected by practitioners.

To enhance CYP's direct participation in research, researchers must prioritise the careful and professional development of their research designs. They need to invest time in building relationships and trust with gatekeepers, demonstrate how they will ensure children's safety and exhibit competence in using appropriate creative methods that can foster meaningful participation. Safeguarding CYP's rights requires enhancing researchers' competence in working with CYP and improving practitioners' knowledge of childhood studies and the concept of participation. Such efforts are necessary to challenge dominant protectionist attitudes among practitioners that limit CYP's actual opportunities to influence their lives and circumstances.

Keywords:

Children, Creativity, Gatekeeper, Participation, Protection, Rights

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Contents

List of Abbreviations

CYP	Children and Young People
UNCRC	The United Nations Convention on the Rights of the Child

List of Figures

List of Tables

List of Original Papers

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals:

I. Árnadóttir, H. A., Kristinsdóttir, G., Seim, S. & Vis, S. (2023). Challenges for researchers when getting access to children and young people and their consent in research. A scoping review. Nordic Social Work Research, 4(14). 1–15. https://doi.org/10.1080/2156857X.2023.2290129

II. Guðrún Kristinsdóttir & Hervör Alma Árnadóttir (2015). Gatekeeper – what is your role? Children´s participation in research. Netla – Online Journal on Pedagogy and Education. http://netla.hi.is/greinar/2015/ryn/002.pdf

III. Árnadóttir, H. A., Kristinsdóttir, G. & Seim, S. (2025). Invisible children and young people in Child Protection Services. European Journal of Social work, 1–12. https://doi.org/10.1080/13691457.2025.2493317

IV. Árnadóttir, H. A. & Einarsdóttir, M. M. (2023). Using Community Art to Encourage Children to Participate in Discussions About Violence. In Roth, M., Alfandari, R. & Crous, G. (Eds.) Participatory Research on Child Maltreatment with Children and Adult Survivors. Emerald Publishing Limited, 145–162. https://www.emerald.com/insight/content/doi/10.1108/978-1-80455-526-220231010/full/html

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Declaration of Contribution

We, the undersigned, hereby confirm our contributions to the following work:

I, Hervör Alma Árnadóttir, have been involved in all parts of the research projects presented under the guidance of my supervisor Guðrún Kristinsdóttir and co-supervisors Sissel Seim and Svein Vis. All parties performed the project design, revision and final conception.

Paper I: Challenges for researchers when getting access to children and young people and their consent in research. A scoping review. Hervör Alma collected, analysed and interpreted the data and drafted the manuscript. All the authors contributed to the analysis and interpretation of the data, as well as drafting and revising the manuscript. All authors read and approved of the final manuscript.

Paper II: Gatekeeper—what is your role? Childrens participation in research, was carried out by Hervör Alma in collaboration with a Guðrún Kristinsdóttur supervisior. Hervör Alma under Guðrúnar Kristinsdóttur supervision, was the leader in the focus group interviews, analysed and interpreted the data, authored drafting on the manuscript. Hervör Alma and Guðrún Kristinsdóttir together worked on the reviewing process and revising the manuscript. Both the authors reviewed and approved the final manuscript. In article II, alphabetical was used when listing authors.

Paper III: Invisible children and young people in Child Protection Services. Hervör Alma collected the data, analysed, and interpreted the data, and drafted the manuscript. Sissel Seim and Guðrún Kristinsdóttir contributed to the analysis and interpretation of the data, as well as drafting and revising the manuscript. All authors read and approved of the final manuscript.

Paper IV: Using Community Art to Encourage Children to Participation in Discussions About Violence. The data analysis and interpretation was carried out by Hervör Alma in collaboration with a graduate student, Martha María Einarsdóttir, who contributed to the analysis and interpretation of the data as well as drafting and revising the manuscript. Both authors read and approved of the final manuscript.

This thesis was written using Grammarly, an English language writing assistant software tool that provides stylistic guidance, rewriting suggestions and tone adjustments.

Sincerely, Hervör Alma Árnadóttir

1 Introduction

The research project which forms the basis of this thesis is titled "Participation of Children and Young People in Research. Opportunities and challenges". The project aims to increase knowledge and understanding of how children and young people (CYP) can be supported to participate in social research on issues that concern them.

The project is based on three peer-reviewed papers and one peer-reviewed book chapter. Data were collected in a period of seven years, from 2015 to 2023. Paper I, which explores the state of knowledge in the field, draws on data from peer-reviewed articles published between 2015 and 2021. The data in Papers II and III consist of qualitative semi-structured focus group interviews, which are well suited to examining shared experiences or interests. The participants were professional practitioners working with CYP in child protection services, as well as researchers with experience of conducting research involving CYP. Finally, the book chapter discusses the usefulness of creative methods when working with CYP, using data collected from CYP themselves.

There is a growing emphasis within welfare services on the need for practitioners to engage with research findings to guide and enhance their practice. To provide the best possible support, practitioners are expected to be familiar with evidence-based approaches that have been shown to be effective when working with individuals, including CYP. This includes offering advice grounded in research and using this knowledge to empower and support those they work with (Drisko & Grady, 2015; Guðmundsson & Árnadóttir, 2019; Perry-Hazan, 2016). Although social workers often express positive attitudes towards integrating research into their work, they frequently encounter challenges in applying research findings to real-life decision-making processes (Gudjonsdottir et al., 2017). Nevertheless, as the focus on research-informed or evidence-based practice continues to grow, these findings are increasingly shaping important decisions about the lives and environments of CYP.

The United Nations Convention on the Rights of the Child (UNCRC; 1989) affirms that CYP, capable of participating by forming their views, have the right to express those views freely. They have the right to seek, receive and impart information and ideas in all matters affecting them. These rights recognise CYP as active agents in their lives whose opinions should be taken seriously according to their age and maturity. Hart (1992) expands on this idea by suggesting that participation should not be limited to individual expression but should also include opportunities for collective engagement. He argues that CYP should be encouraged to participate in decision-making processes at a group or community level, highlighting the importance of shared experiences and

democratic involvement. In this way, CYP's participation is framed not only as a personal right but also as a step towards inclusive social practices. Even though adults can provide valuable insights into the concerns of CYP, findings in childhood studies show that adults may not always be fully aware of what CYP know, experience or understand (Bradbury-Jones, Isham & Taylor, 2018; Spyrou, 2011, 2019). Relying solely on adults' perspectives when seeking information could lead to misunderstanding CYP's needs. Therefore, the participation of CYP in research is necessary to understand their unique experiences, culture and reality in order to meet CYP's needs and beliefs (Brady, Shaw & Blades, 2012; Carter, 2009; Kurt, 2022; Perry-Hazan, 2016; Stafford et al., 2021).

When arriving at the point of selecting the topic for my PhD thesis, my previous research and experience as a social worker inspired me to look in more detail into how Icelandic CYP – especially those receiving support from children's social and protective services – can be guided to take an active part in important decisions that could affect their own lives and in research.

I have broad experience of working with CYP involved in Iceland's social services and education services as a social worker and teacher for two decades. At the same time, I have also been involved in management and served as a lecturer in social care at different levels of the educational system, currently as an associate professor in the faculty of social work at the University of Iceland. Because of this, conducting research and writing papers has been a big part of my work over the last almost 20 years.

My research focus has been on the participation of CYP in social services, nature therapy with at risk youth, evidence-based practice in social work and how one can include research findings in everyday work for service users' benefit, not least CYP. In my practice as a social worker I have observed that CYP can easily become marginalised, especially those living in difficult social circumstances. My previous research has confirmed a lack of meaningful participation and influence for CYP at risk (Árnadóttir, 2008; Kristinsdóttir & Árnadóttir, 2023; Árnadóttir & Einarsdóttir, 2018; Árnadóttir & Ólafsdóttir, 2019; Árnadóttir & Andrésdóttir, 2024; Árnadóttir & Jónsdóttir, 2025). Research studies have underlined that CYP often experience a lack of empowerment and are unable to influence matters that concern them and also that they are excluded from taking part in important decisions in matters that can have a significant impact on their lives (Checkoway, 2011; Dillon et al., 2015; Toros & Falch-Eriksen, 2021).

The central perspective of this PhD thesis is CYP's participation, with a particular emphasis on their opportunity to be involved in research. However, it is also essential to address CYP's participation more broadly in decisions affecting their lives and circumstances and I aimed to connect this project to CYP's participation in research. CYP's participation in research constitutes a key aspect of upholding their right to express their views and be actively involved in matters that concern them, as articulated

in Article 12 of the UNCRC (1989). In line with the principles of participatory approaches, this requires a clear conceptual understanding of what participation entails, including the recognition of CYP as social agents with valuable perspectives (Lundy, 2007; Percy-Smith & Thomas, 2010). CYP's participation also requires identifying appropriate and meaningful methods to facilitate such engagement (Shier, 2001, 2019) and a genuine commitment to recognising and valuing CYP's agency and competence (James et al., 2012; Mayall, 2009, pp. 20–21).

Current research findings indicate a significant gap in the inclusion of marginalised CYP in social research, particularly those receiving support from child social services and child protection services (Cojocaru, 2013; Fleming, 2011; Garcia-Quiroga & Agoglia, 2020; Perry-Hazan, 2016). Access to these groups remains limited due to recruitment challenges and the influence of gatekeepers (Merkel-Holguin et al., 2019; Watson et al., 2018). Practitioners in the role of gatekeepers often prioritise protection over participation, viewing these concepts as oppositional rather than complementary (Dempsey et al., 2016; Lundy, 2007; Sandberg, 2018; Vis, Holtan & Thomas, 2012).

Due to the limited literature on the challenges associated with conducting research involving CYP, it is important to fill this knowledge gap, and I therefore chose the topic of CYP's participation in social research.

In Iceland there is limited qualitative research involving CYP who have received support from social welfare or child protection systems. In 2003 I commenced a master's degree in social work with the aim of exploring the lived experiences of CYP in vulnerable circumstances. I was invited to participate in a Nordic research project focusing on family group conferences from CYP's perspective. Gaining access to participants proved challenging. After more than two years of attempting to reach CYP, I was finally able to invite three CYP to participate in the study, all of whom expressed interest in participating. I followed these CYP through the family group conference process, conducted interviews and engaged in participatory observation. This experience underscored the complexities of negotiating access through gatekeepers: an issue that continued to preoccupy me. Consequently, I chose to examine this topic more systematically in my doctoral research.

Research within the field of child protection and social services has primarily been conducted by scholars and master's students in the faculty of social work at the University of Iceland. In the faculty of social work at the University of Iceland, in Skemman, from 2020 to 2025, 177 theses were submitted, most focusing on social difficulties and people's circumstances. Only one of these studies included direct participation of CYP in the research process.

Therefore, there is a clear rationale for exploring in greater depth the challenges researchers face when conducting qualitative research on the experiences of CYP who have received support from the social system.

1.1 The Icelandic context

In 2025 Iceland's population is 389,444. In 2022 there were 83,082 inhabitants aged 0–18 years (Statistics Iceland, e.d.), referred to here as CYP. Of these, 33,588 CYP were aged between 11 and 17 years. In 2021 a total of 3,190 CYP aged 11–18 years received support from child protection services in Iceland (Statistical information from child protection committees, 2024).

1.1.1 Legal context regarding children and young people's rights in Iceland

The UNCRC (1989) significantly influenced the Icelandic Child Protection Act (2002). Following its ratification in 2013, the legal status of CYP was strengthened, particularly concerning their rights to participation and self-expression (Friðriksdóttir & Gísladóttir, 2015).

This shift aligns especially with Articles 12 and 13 of the UNCRC, which emphasize CYP's rights to be heard and to express their views freely.

According to the Icelandic Child Protection Act (No. 80/2002), CYP are legally defined as individuals under the age of 18. However, it is unclear when and how children have the right to more active participation in child protection matters. CYP aged 15 and older are explicitly recognised as parties in child protection cases, while parents must be consulted if a child under 12 years old is interviewed or observed. No legal provision defines whether younger children can also be considered parties in similar cases. Kristinsdóttir (1992) criticises this age limit, questioning why this threshold was chosen.

Both the Children's Act (No. 76/2003) and the Child Protection Act (No. 80/2002) emphasize that CYP have a right to participate in decisions affecting them. Depending on their level of maturity, CYP should have opportunities to express their views and their opinions should be considered when making decisions, provided CYP's opinions are not harmful or irrelevant to their future well-being. However, the absence of a clear legal standard for assessing maturity and participation rights creates inconsistencies in practice. Addressing these gaps through clearer legislation and implementation guidelines would strengthen CYP's rights in practice, not just in principle.

Social services in Iceland operate on a locally-based service-oriented ideology with a low threshold for intervention. The primary goal is to ensure a safe and healthy environment that supports the well-being of CYP and their families (Eydal & Rostgaard, 2011; Social Services Act, No. 40/1991). CYP in need of health, education or social care services should receive support from practitioners, who are responsible for improving their quality of life. These practitioners must always act in the child's best interest, as outlined in the Child Protection Act (No. 80/2002) and the Social Services

Act (No. 40/1991). The concept of a child's best interest has been subject to debate. In this context, Skivenes and Sørsdal (2018) argue that only individuals themselves can determine what brings them happiness and well-being. Therefore, a child's best interests should be defined in collaboration with CYP.

1.2 Overview of the PhD research project

In this part I will provide an overview of the PhD research project, starting with the purpose, aims and research questions, followed by a description of the theoretical framework and the methodological approach.

1.2.1 The purpose, aims and research questions

This PhD thesis focuses on CYP's opportunities to participate in social research. In this project CYP are taken to include anyone under the age of 18, in accordance with the UNCRC (1989). Emphasis is on CYP 10–18 years old, even though sometimes there is a reference to research with CYP in a broader sense.

The general aim is to increase knowledge and understanding of how CYP can be supported to participate in social research on issues that concern them. With increased knowledge of the challenges that arise when conducting research with CYP's participation and how researchers overcome those barriers, it is my hope that research with CYP will increase, which may lead to better addressing CYP's needs in the development of services, individual support and policies.

I approach the project's theme – the challenges of involving CYP in social research – from several angles: by conducting a scoping review of the literature, exploring the experiences of researchers who work with CYP in social research and examining the perspectives of practitioners in social services who are approached by researchers seeking to include CYP as participants. To address these challenges, the study also presents and discusses visual and creative methods that may be useful for engaging CYP in conversations about sensitive topics within research settings.

1.2.2 Specific aims

The specific aims of this research are:

- Investigating the knowledge and challenges faced by researchers when working on CYP's participation in social research, through a scoping review of the literature on the topic (Paper I).

- Exploring the experiences of researchers who have gained access to institutions and support from gatekeepers, enabling them to involve CYP as active participants in research (Paper II).

- Examining how practitioners manage the balance between participation and protection and perceive their roles as gatekeepers when researchers seek access to CYP (Paper III).

- Identifying useful methods for supporting CYP in discussing sensitive issues in social research settings (Paper IV).

1.2.3 Overall research questions

The following overall research questions guided the project:

1. What ethical and methodological challenges do researchers need to overcome in order to obtain support of gatekeepers to gain access to CYP for participation in social research?

2. How do practitioners in child protection services understand the practical implications of CYP's participation in social research?

3. How can research methods be adapted to overcome the challenges of involving CYP in research?

Table 1 below shows how the research questions in Papers I, II, III and IV (horizonal) relate to each of the three key research questions (vertical).

Table 1. The key research questions' relation to the papers' research questions.

The key research questions ↓	Paper I →	Paper II	Paper III	Paper IV
What ethical and methodological challenges do researchers need to overcome in order to obtain support of gatekeepers to gain access to CYP for participation in social research?	What are the main challenges researchers must overcome when seeking access to CYP and getting their consent in welfare research?	What is the researchers' experience in gaining access to CYP to request their participation in research?	How do social workers balance participation and protection when supporting CYP's participation in research? How do social workers understand their roles as gatekeepers?	
How do practitioners in child protection services understand the practical implications of CYP's participation in social research?	What are the main challenges researchers must overcome when seeking access to CYP and getting their consent in welfare research?		How do social workers balance participation and protection when supporting CYP's participation in research? How do social workers understand their roles as gatekeepers?	
How can research methods be adapted to overcome the challenges of involving CYP in research?	What are the main challenges researchers must overcome when seeking access to CYP and getting their consent in welfare research?			How do CYP express themselves about sensitive topics such as abuse and violence? Can community art enable professionals to better support increased participation of CYP in discussions about abuse and violence?

2 Theoretical framework

The theoretical framework of this study draws upon insights from different theoretical perspectives on the understanding and definition of childhood, protection, participation and models that address issues related to conducting research with CYP in an ethical and purposeful manner. First, I will introduce my philosophy of science standpoint, followed by a discussion on childhood and theories positioning CYP as competent individuals.

The philosophy of science standpoint adopted in this thesis is grounded in social constructionism. Social constructionism posits that realities are not inherent or objective, but rather socially constructed through language, symbols and shared meanings within particular social and cultural contexts. These contexts shape perceptions of identity and reality. The social constructionist perspective suggests that people and societies create and maintain knowledge, beliefs and understanding through interactions and negotiations, meaning that everyone's reality is unique, shaped by their experience, culture and context (Berger & Luckmann, 1966). As a result, people's views and opinions about what is 'real' may shift depending on the individuals involved or the passage of time (Andrews, 2012; Dunk-West, 2013).

Adopting a critical social constructionist view means seeing the world through the lens of social determinants such as power, freedom and repression (Creswell, 2013). The critical social constructionist view portrays CYP as active and capable individuals who can play an essential role in shaping their social environments. Contemporary theories about CYP and childhood have been significantly influenced by social constructionist perspectives (Corsaro, 2011, pp. 7–29). The understanding of reality is fluid, continually evolving, and thus requires continuous review. Given that CYP's realities are perceived as unique, their voices need to be heard to understand their realities and circumstances at any time. Two crucial question are how and when CYP are competent enough to participate in decisions about their own lives. While some countries, such as Iceland, have introduced the age limits into legislation, James et al. (2012, pp. 73–75) critique the reliance on fixed age criteria in determining CYP's participation, arguing that such measures can obscure CYP's actual competencies. They emphasize that childhood is socially constructed and that participation should be based on context and capability rather than age alone.

2.1 Childhood studies

Childhood studies is an interdisciplinary field, bringing together theories and methods from multiple academic disciplines, such as sociology, psychology, education, law and

health sciences, to gain a deeper and more holistic understanding of childhood. This approach recognises that CYP's lives are complex and shaped by a variety of social, cultural, historical and biological factors, and appears among other things in differences in legal frameworks and regulatory systems (James et al., 2012, pp. 73–75; Mayall, 2009, pp. 9–26). This evolution has resulted in contrasting views on CYP's engagement and safeguarding, marking a shift from traditional paradigms that viewed CYP as passive recipients of adult authority to models that advocate for their active involvement in decision-making processes (Fern, 2012; James & Christensen, 2008). Tisdall (2017) highlights a significant shift towards models that advocate for CYP's active participation in decision-making processes. She examines how contemporary frameworks, rooted in co-production and social accountability, challenge older paradigms and promote more equitable power dynamics between adults and CYP.

The evolving understanding of childhood has influenced recent scholarship, leading to a reconceptualization of CYP as active participants in their own lives. Moving beyond traditional views that positioned CYP merely as passive recipients of adult guidance and protection, contemporary perspectives emphasize the dynamic and complex nature of childhood (James et al., 2012; Mayall, 2009). Within this framework, CYP are increasingly regarded as both "beings" and "becomings"; not only individuals with present needs and experiences, but also as socially aware actors who actively engage with and shape their future trajectories (Neale & Flowerdew, 2007; Njøs & Seim, 2019; Raghavan & Alexandrova, 2015).

This dual perspective challenges age-based assumptions about competence and instead foregrounds the experiential and cognitive capabilities of CYP. Scholars such as Alderson (2007) and Corsaro (2019) argue that CYP possess the capacity to reflect, contribute and make meaningful decisions, particularly when their lived experiences are recognised as valid forms of knowledge. This shift from a protectionist to a rights-based discourse positions CYP not solely as vulnerable but as rights holders with the ability and right to participate in decisions affecting them.

Moreover, this evolving view is enriched by the growing emphasis on relationality and materiality in childhood studies. Relationality focuses on the ways CYP form and navigate relationships with others, while materiality draws attention to the physical, social and institutional environments they inhabit (Mannion, 2007; Spyrou, 2019; Woodgate, Tennent & Zurba, 2017). Together, these dimensions underscore the contextual and fluid nature of childhood, illustrating how CYP's experiences are shaped by and help shape the world around them.

Qvortrup (1994) describes childhood as a multifaceted construct, encompassing both sociocultural and economic dimensions during the formative years. Philippe Ariès's conceptualisation of childhood as socially constructed revolutionised the understanding of childhood, challenging deterministic views and influencing fields like social work to critically reflect on how childhood is shaped by societal forces (Ariés, 1962). Ariès's

ideas have had significant implications for discussions on the rights and agency of CYP, advocating for a perspective that acknowledges their ability to participate in shaping their own lives.

2.1.1 Respect for children and young people's rights

Scholars have questioned what prevents CYP from being recognised as competent participants (Thomas, 2012). Honneth's theory of recognition (1995) provides useful insight into participation, when linking participation to mutual recognition. Honneth identifies three forms of recognition: love, rights and solidarity.

Love refers to primary relationships in which individuals meet each other's needs. This form of recognition is essential for the development of self-confidence, trust and social skills. Rights concern personal autonomy and the legal recognition of individuals, leading to the development of self-respect and dignity. Solidarity involves intersubjective relationships where individuals mutually sympathise with one another and recognise each other's unique qualities (Honneth, 1995).

Thomas (2012) has explored how Honneth's theory can support us in understanding both the practical and theoretical implications of CYP's participation. Thomas argues that all three forms of recognition are necessary for CYP's involvement. CYP must feel unconditional love, be recognised as legal rights-holders and experience a sense of belonging to a social world.

In a similar vein, Fieller and Loughlin (2022) discuss the issue of stigma and the need for a new language when working with CYP. They argue that rather than referring to CYP as "children in care", they should be addressed more personally, by name, and that we should avoid institutionalised language. They emphasise the importance of developing better listening skills and showing respectful attitudes towards CYP's narratives. With regard to Honneth's theory, the points raised by Fieller and Loughlin (2022) can also be understood as a call for deeper forms of recognition in work with CYP. Their emphasis on moving away from institutional language and towards respectful, individualised communication reflects a desire to affirm CYP's dignity and personhood, central to Honneth's notion of rights. The importance they place on better listening to CYP and acknowledging their lived experiences can be interpreted through the lens of solidarity, recognising their unique experiences and perspectives. Together with the foundational role of love, manifested in the need for care, emotional security and acceptance, these insights align with Honneth's three dimensions of recognition, all of which are essential for fostering genuine participation and belonging among CYP.

2.2 Participation

Participation, a central concept in this thesis, is one of the core principles of the UNCRC, asserting that CYP have the right to freely express their views and that there is an obligation to listen to them in all matters affecting them. Before discussing CYP's participation in research – the main subject of this thesis – it is inevitable to begin by discussing in general terms the definitions of participation, how different scholars have discussed participation and how it is possible to implement it in different contexts.

2.2.1 Participation and protection

Participation among CYP is a complex, multifaceted concept shaped by cultural, legal and institutional contexts (Shier, 2019; Spyrou, 2018). While definitions vary, a common thread across the literature is the emphasis on CYP's right to participate and the importance of making that participation meaningful (Seim & Slettebø, 2017).

Participation brings two central benefits: it improves the quality and relevance of services and supports CYP's personal development. When CYP contribute to designing social support services, those services are more likely to meet their actual needs compared to services created solely by adults (Fleming, 2011; Gallagher et al., 2012; Head, 2011; Sæbjørnsen & Willumsen, 2017; Woolfson et al., 2009). Furthermore, the process of participation itself can strengthen CYP's self-esteem, enhance their well-being and increase their understanding of their own circumstances (Vis et al., 2011). Despite these benefits, CYP are frequently excluded from decision-making forums in child protection and social services. Practitioners and managers often decide who participates in meetings, and CYP's absence may result in the loss of valuable perspectives (Garcia-Quiroga & Agoglia, 2020; Kosher & Ben-Arieh, 2020; Tunestveit, Njøs & Seim, 2022; van Bijleveld, Dedding & Bunders-Aelen, 2015). Including CYP is vital to ensure that services align with their needs, as an understanding of their perspectives is key to service quality (Hill et al., 2004; Seim & Slettebø, 2010; Tunestveit et al., 2022).

While research often focuses on the outcomes of CYP participation, less attention has been given to how meaningful participation is actually achieved in the process (Alderson, 2007; Fern & Kristinsdóttir, 2011; Morrow, 2008). Jørgensen, Seim and Njøs (2024) highlight that CYP view participation as a relational and collaborative process, requiring age-appropriate information, consistent communication and the ability to influence decisions that affect them. A supportive, trusting relationship with professionals is key to fostering participation and agency. Participation is not merely procedural but also relational and emotional. van Bijleveld et al. (2015) and Pölkki et al. (2012) describe meaningful participation as a dialogical and situational process involving all stakeholders. Fern (2008, 2012) advocates for a child-directed approach where CYP are considered central actors in decision-making. In this model, CYP

engage directly in dialogue with professionals and family members, contributing as equal partners.

The UNCRC outlines both the right to participation (Article 12.1) and the right to protection (Article 3.2). These principles can be perceived to be in tension with one another, especially in CYP welfare settings. If protection and participation are not understood as interconnected and mutually dependent, but rather as opposing concepts (Toros & Falch-Eriksen, 2021), this can result in CYP being overprotected, which may silence them and deny them the opportunity to influence their own lives and circumstances (Daley, 2015; Fern, 2012; Garcia-Quiroga & Agoglia, 2020; Heimer, Näsman & Palme, 2018; Kennan & Dolan, 2017). It has been argued that the tendency towards overprotection of CYP is closely linked to paternalistic ideologies and a "we know best" attitude, at the expense of using empowering approaches to meaningful participation (Kosher & Ben-Arieh, 2020; Tunestveit et al., 2023; Vis et al., 2012). Sandberg (2018) argues that genuine protection cannot exist without participation. To uphold CYP's dignity and rights, professionals must strike a balance between these obligations and recognise participation as essential to effective protection.

In conclusion, participation must be understood as a dynamic, relational practice that extends beyond formal procedures. It requires commitment to listening, shared decision-making and an environment where CYP feel valued and safe. Embedding these principles into research settings and practice can enhance both services and the well-being of the CYP they are designed to support.

2.2.2 Participation models

Understandings of how participation should be implemented differ considerably, with some approaches emphasising social interaction, while others rely on formal models based on age and cognitive development (Lundy, 2007; Hart, 1992; Shier, 2001). Hart (1992, pp. 5–9) developed an influential model based on Arnstein's (1969) Ladder of Citizen Participation, adapting it to reflect CYP's participation. Hart's model ranges from non-participation, where CYP have no influence, to CYP´s initiated, shared decision-making with adults, where CYP exercise full control over processes and outcomes. Hart views participation as a process involving both responsibility and choice, not merely the expression of opinion. However, his model has been criticised for being overly linear and failing to capture the complex and context-dependent nature of participation (Thomas, 2000, pp. 174–175). In a later revision Hart (2008, p. 8) acknowledges the importance of situational diversity and cultural variation in shaping CYP's everyday participation, factors not fully addressed in his original model. Shier (2001, pp. 111–115) advanced Hart's work by focusing more explicitly on practical implementation. He omitted Hart's non-participation levels and instead started from the point where CYP are actively listened to and their views are taken seriously.

Shier emphasises the creation of structured opportunities for CYP to participate in ways appropriate to their abilities and developmental stages. His model introduces three dimensions at each level of engagement: openings, when practitioners acknowledge the value of participation; opportunities, when practitioners have the knowledge and skills to support participation; and obligations, when participation becomes embedded in organisational policy or practice. For example, institutions may adopt formal policies guiding how practitioners support researchers when accessing CYP who receive support.

Lundy (2007) presents a rights-based model rooted in the UNCRC (1989). She argues that CYP should not only be able to express their views but also have a genuine influence on decision-making. Her framework is built around four interrelated concepts designed to ensure that participation is meaningful rather than merely symbolic: space, voice, audience and influence. This means that CYP must be provided with a safe and inclusive space to express their views. They need support in articulating those views. Someone must actively listen to them, and their views must be acted upon and have an impact on decisions.

Bouma et al. (2018) build their model on ethical issues and relationships. The model emphasises key principles such as respect, transparency, negotiation and attention to context, all of which are essential in building trust. Like Lundy, Bouma et al. (2018) emphasise meaningful participation as an ongoing process, beginning with the identification of an issue and culminating in decision-making. Their definition sees CYP as active participants in matters affecting their lives, with a focus on their right to influence governance and administrative processes. They stress the importance of embedding CYP's input into real, consequential decisions.

While Hart (1992, 2008) focuses on structural levels of participation towards shared decision-making, Bouma et al. frame participation as an ethical process embedded in relationships and situated in the lived realities of CYP. Bouma et al. (2018) expand on Hart's work by moving from a primarily hierarchical view of participation to one that prioritises ongoing dialogue and ethical engagement. This shift aligns with broader developments in the field that recognise participation not merely as a matter of structure or access, but as a relational and moral practice shaped by the quality of adults' and CYP's interactions and institutional commitment to meaningful participation.

Table 2. Emphasis in participation models.

Model	Focus	Structure	Strength	Limitation
Hart (1992)	Levels of participation	8-step ladder	Shows power dynamics and helps recognise tokenism	Linear and hierarchical
Shier (2001)	Organisational readiness	5-level pathway	A practical tool for moving towards meaningful participation	Adult and organisational driven rather than CYP's definitions of participation
Lundy (2007)	Implementation of UNCRC	4 concepts and rights based	Emphasises structural conditions; useful for practice and policy	Created for formal systems like education rather than community-based participation context
Bouma et al. (2018)	Ethical and relational	Built on principles	Focus on ethical engagement and CYP agency; could be useful in research contexts	Lacks clearness or structure

2.3 Children and young people's participation in social research

Despite growing interest in CYP's rights, their participation in research remains inconsistent or entirely absent, among those who are already marginalised and most affected by adult decision-making. CYP in vulnerable situations, such as those receiving support from child protection services, are often the least heard, despite adult decisions having profound impacts on their lives (Aldridge, 2017; Powell et al., 2020). Building on these evolving models of participation, there has been a parallel shift in

how CYP are engaged in research. The movement from viewing participation as a structured ladder or checklist towards a relational, rights-based and ethically grounded process has influenced both practice and research methodologies. These developments challenge traditional adult-centric approaches and call for the inclusion of CYP as active contributors when seeking knowledge. Rather than conducting research on CYP or interpreting their experiences solely through adult lenses, the emphasis has increasingly shifted towards research conducted with or by CYP. This reflects a broader understanding that their perspectives may differ significantly from those of adults, and that their experiences, needs and desires are best expressed in their own voices, through creative and participatory methods (Clark & Moss, 2017; Kurt, 2022). Christensen and Prout (2002, pp. 480–481) identify four key perspectives on the role of CYP in research: as objects, subjects, social actors and participants or co-researchers. These perspectives reflect an evolving understanding of CYP's roles, from passive recipients of adult interpretation to active agents in knowledge production. The traditional view sees CYP as objects, based on adult-centric assumptions about vulnerability and incompetence, which often excluded their voices. More recent perspectives challenge these assumptions, recognising CYP as individuals with subjectivity (subjects), capable of agency and social influence (social actors), and ultimately as active participants or even co-researchers.

In continuation of his earlier work on CYP's participation in decision-making (Shier, 2001), Shier (2019) extends his framework to the context of research involving CYP. This shift aligns with the UNCRC, especially Article 12, which upholds CYP's right to be informed, consulted and involved in decisions affecting them, including research. Shier (2019, pp. 295–315) builds on this foundation with a model of CYP's participation in research that ranges from not being involved at all to being consulted, collaborating with adult researchers and ultimately directing research processes. His accompanying tools invites researchers to reflect on power dynamics, roles and relationships to foster mutual respect, shared decision-making and ethical engagement with CYP. This approach encourages deeper collaboration and helps identify structural and relational barriers to meaningful involvement.

A growing body of work (Fern & Kristinsdóttir, 2011; Fern, 2012; James & Prout, 2015; Kellett et al., 2004; Kellett, 2005, 2010, 2011) critiques traditional, adult-dominated research paradigms and advocates for participatory approaches that position CYP as capable contributors to research and knowledge. However, the involvement of CYP as co-researchers is not without controversy. Some scholars have questioned whether untrained individuals, particularly CYP, should undertake research, arguing that this risks devaluing the formal expertise of professional researchers (Alderson, 2012). In contrast, Lundy and McEvoy (2012) maintain that the UNCRC provides a strong basis for CYP's active involvement. They argue that participation must go beyond tokenism to ensure CYP have real influence over the research process and its outcomes.

2.3.1 Permission and consent

Research involving CYP requires careful consideration of both methodological and ethical approaches. Central to this is ensuring that participation is both authorised and meaningful. Permission, typically granted by a parent or legal guardian, is the formal approval required for CYP to be involved in a research study. This step is essential to confirm that a responsible adult has been fully informed of the research's purpose, potential risks and expected benefits (Hill et al., 2004).

In tandem with permission, informed consent is a core ethical requirement and a marker of professional conduct in research. It refers to the voluntary agreement of a participant or their legal representative regarding their participation in a study after receiving clear and comprehensive information about what participation entails (Hill et al., 2004; Alderson, 2007). According to the University of Iceland Research Ethics Committee guidelines (2014), informed consent must generally be obtained from a parent or legal guardian for participants under 18 years of age. This process should be transparent, with clear communication of the study's aims, procedures, potential risks and the safeguards in place to protect the CYP.

However, formal permission and consent are not sufficient on their own. Assent – the CYP's own agreement to participate – is ethically significant, particularly in recognising CYP's evolving capacities and agency. While assent does not carry legal weight, it acknowledges the child's right to express their willingness or unwillingness to participate. Researchers must therefore provide appropriate information and create supportive spaces that enable CYP to make informed choices (Graham & Fitzgerald, 2010; Morrow, 2008).

In practice, this can involve the use of creative and participatory methods to ensure that consent is not treated as a one-off event but rather as an ongoing, collaborative process. Moore, McArthur and Noble-Carr (2018) describe the use of child-friendly materials and sustained dialogue to make consent accessible and meaningful throughout the research. Woodgate et al. (2017) discuss the competence of researchers when highlighting the importance of sustaining a mindful presence when working with CYP. This approach calls for researchers to remain open, curious, empathetic and reflexive, attuned to the verbal and non-verbal cues that CYP express. By being mindful in this manner, researchers can better identify and respect CYP's boundaries, foster safe and empowering research spaces and ensure that participation remains both informed and voluntary. Sustaining a mindful presence thus supports ethically responsible research that upholds the rights, agency and well-being of CYP.

2.3.2 The role of gatekeepers

Researchers seeking to involve CYP in social research need to navigate a complex hierarchy of gatekeepers in order to gain access to the target group. Gatekeepers are

individuals or institutions that control access to potential participants (Jupp, 2006/2013, p. 126). Access refers to the process of obtaining approval to approach or work with individuals in the context of social research (Jupp, 2006/2013, pp. 1–2). Common gatekeepers include parents, guardians, teachers, social workers and CYP welfare agencies. They play a dual role: on one hand they are responsible for protecting CYP from potential harm, while on the other they have the authority to either facilitate or restrict researchers' access (Danby & Farrell, 2010; Jupp, 2006/2013; McLaughlin, 2007). This dual role often causes tension between protection and participation and presents a critical challenge, particularly in contexts where concerns about vulnerability overshadow recognition of CYP's rights to be heard.

Seeking access is not a single event but an ongoing and dynamic process that may require repeated negotiation throughout the research project. Securing access typically involves permission from ethics committees and relevant authorities such as parents, guardians, teachers or social workers. It may also involve building relationships with institutions and professionals who work directly with CYP, such as educators or welfare practitioners (Graham & Fitzgerald, 2010; Jupp, 2006/2013). Kyritsi (2019) discusses the importance of respecting the rights of CYP as set out in the UNCRC and presents how creative methods can be used to actively work in access processes by using symbolic boxes representing agreement or refusal, to ensure that CYP's participation is voluntary and informed at all times.

Navigating relationships with gatekeepers to gain access can be both complex and time-consuming. Researchers must establish trust and maintain open, transparent communication to secure gatekeepers' support. This often involves aligning the research goals with the values and concerns of gatekeepers, who may be cautious or hold competing priorities (Alderson & Morrow, 2011; Martins, Oliveira & Tendais, 2018; Powell et al., 2020; Reeves, 2010; Turner & Almack, 2017). However, the process is frequently shaped by institutional barriers and risk-averse attitudes, making it both time-consuming and unpredictable. As a result, many CYP are excluded from opportunities to participate directly in research, particularly those whose voices may be most marginalised (Checkoway, 2011; Dentith, Measor & O'Malley, 2009; Garcia-Quiroga & Agoglia, 2020).

Gatekeepers do more than control access, they also shape how CYP and their families perceive the research. They may influence participation by explaining the study, addressing concerns or even encouraging or discouraging involvement. As such, researchers should collaborate closely with gatekeepers, ensuring they are well informed, ethically engaged and respectful of CYP's right to make informed choices about participation.

Conducting research with CYP requires careful attention to both ethical and practical considerations, including permission, informed consent and assent. These elements are essential not only for safeguarding CYP but also for upholding their rights as

participants. In this context Bouma et al.'s (2018) relational model (Table 2) provides a valuable framework for navigating the often complex relationships with gatekeepers and CYP. The model emphasises mutual respect, negotiation and contextual awareness – crucial principles when working with adult stakeholders who may be protective or hesitant. By approaching gatekeepers as partners rather than obstacles, researchers can foster a more ethical, inclusive and effective research process.

Ultimately, gatekeepers are essential to facilitating ethical research with CYP. Their cooperation is often a prerequisite for obtaining access, consent and assent. However, their involvement also underscores the importance of carefully navigating adult-child dynamics to uphold the rights of CYP and support their meaningful participation in research.

2.3.3 Creative methods

When CYP take part in research, the researcher has the responsibility to use appropriate methods to ensure that the study is in the best interest of the CYP. Chosen methods should be child friendly, safe to work with and not put CYP at risk (Buser, 2024; Fleming, 2011; Garcia-Quiroga & Agoglia, 2020). Creative methods offer flexible approaches when meeting diverse needs by engaging cognitive, emotional and sensory aspects of experience (Buser, 2024; Bos, 2019; Huss & Sela-Amit, 2018). Methods such as drawing, mapping and using photos are increasingly used to acknowledge CYP and recognising them as active participants with valuable insights into their own lives (Christensen & James, 2017). Creative methods can be useful with CYP in vulnerable situations, such as those involved in child protection and social services (Bos, 2019; Lomax, 2012; Spyrou, 2011). While creative methods offer rich and empowering possibilities, they must be applied with ethical care. Researchers need to consider how creative or visual data will be interpreted, stored and shared, and must ensure that CYP's contributions are represented respectfully and safely (Lomax, 2012).

Several scholars have discussed the ethical challenges faced by researchers working with CYP in qualitative research, particularly regarding the power imbalance between adults and CYP (Bradbury-Jones et al., 2018; Kellet, 2010; Powell et al., 2020). They have noted that the research topics and their presentation often reflect the adult perspective, rather than being child-focused, in line with childhood theory. They have therefore encouraged researchers to be innovative by developing various research approaches and methods (Daley, 2015; Garcia-Quiroga & Agoglia, 2020; Powell et al., 2020).

This chapter has discussed how CYP's participation in research is influenced by the social construction of childhood. Rather than viewing CYP as passive individuals or incomplete adults, it emphasises the importance of recognising them as capable social agents who are shaped by and shape their social contexts. This perspective challenges traditional adult-centred research models and calls for approaches that acknowledge

CYP's autonomy and meaningful participation. Applying social constructivism involves designing research processes that are creative, flexible and responsive to the diverse experiences of CYP, while also taking into account the concerns of gatekeepers, whose emphasis on their protective stance can affect whether and how CYP are provided with opportunities to participate in research.

3 Materials and methods

This chapter focuses on the methodology of my thesis, connecting concepts with upcoming data and outlining how the data were analysed. I will describe the research design, participants and methods used to collect and analyse the data, and conclude by addressing the limitations and ethical issues.

3.1 Research design

I have chosen a qualitative research approach to achieve the aim of increasing knowledge and understanding of how CYP can be supported to participate in social research on issues that concern them. In doing so, I have formulated the following questions:

1. What ethical and methodological challenges do researchers need to overcome in order to obtain support of gatekeepers to gain access to CYP for participation in social research?

2. How do practitioners in child protection services understand the practical implications of CYP's participation in social research?

3. How can research methods be adapted to overcome the challenges of involving CYP in research?

Qualitative methods are valuable for exploring the diversity of social reality and are particularly well suited to examining people's experiences and their understanding of their own realities (Braun & Clarke, 2013). Data were collected through a scoping review to assess existing knowledge, a content analysis of previously gathered data from CYP and focus group interviews with researchers and practitioners in the field of child protection. Focus groups were chosen as a research strategy because the interaction they facilitate enables participants to reflect on and discuss their experiences and perspectives (Malterud, 2019). Another reason is that discussion in a focus group can open up for unexpected aspects of a social phenomenon because the researcher is less able to control the discussion than in an individual interview (Acocella, 2012).

3.2 Participants and data sources

A scoping review (Paper I) was chosen to address the current knowledge about challenges researchers face when conducting research with CYP. The selected articles were published between 2015 and 2021 and the search was undertaken using Scopus

and ProQuest, with CYP as the key issue. For Papers II and III participants were chosen through purposive sampling, ensuring that their characteristics or experiences aligned closely with the research questions. This approach demands careful and critical reflection on the data generated throughout the research (Braun & Clark, 2013).

To study CYP's opportunities to participate in research, the participants (Paper II) were researchers who have experience of working on social research. They were invited to participate in a semi-structure focus group interview to discuss their experiences of the advantages and challenges of involving CYP in research. A semi-structure focus group interview was also chosen to discuss the role of gatekeepers in social research with CYP. The participants (Paper III) were practitioners working with CYP in social services and child protection in Iceland. To study how creative methods can support CYP to talk about sensitive issues such as violence, content analysis notes were collected from CYP after they saw an exhibition with pictures about CYP and violence, with texts from the UNCRC.

The participants in Paper II identified themselves as women, except for one who identified as a man. They were all researchers and had all been working as researchers for over a decade. The participants in Paper III were all social workers who identified as women. The youngest social worker was 25 years old at the time of the interview, and the oldest was 59. Their experience as social workers ranged from 3 to 31 years. All had graduated from the faculty of social work at the University of Iceland, except for one who was educated in Scandinavia.

Although I aimed for a diverse sample, I anticipated a higher proportion of women, because more than 90 percent of Icelandic child protection practitioners are female.

The participants in Paper IV were CYP who visited an art exhibition about children's rights. All elementary schools in Reykjavik, with CYP aged 6–16, were invited to attend the exhibition as part of their education on children's rights.

Table 3. Overview of papers, participants, data, authors and publications.

Papers	Participants	Data	Authors	Published
1. Challenges for researchers when getting access to CYP and their consent in research. A scoping review	Peer-reviewed articles from the years 2015–2021	Findings from 14 qualitative studies	Hervör Alma Árnadóttir, Guðrún Kristinsdóttir, Svein Vis and Sissel Seim	2023
2.Gatekeeper – what is your role? Children's participation in research	Researcher working on social research	Two focus group interviews with eight researchers	Guðrún Kristinsdóttir and Hervör Alma Árnadóttir	2015
3. Invisible children and young people in social research	Practitioner in child protection services	Five focus group interviews with 17 participants	Hervör Alma Árnadóttir, Guðrún Kristinsdóttir & Sissel Seim	2025
4. Using Community Art to Encourage Children to Participate in Discussions About Violence	CYP	Written notes by CYP, 3–16 years old N=630	Hervör Alma Árnadóttir & Martha María Einarsdóttir	2023

Data collection approaches

The data presented in Paper I derive from a scoping review undertaken to explore the current state of knowledge regarding the challenges researchers encounter when involving CYP in research. Data in Papers II and III were collected through semi-structured focus group interviews. This method was chosen to capture a broad range of experiences and perspectives, and to encourage interactive dialogue about CYP's participation in research, researchers' access and practitioners' understanding of their role as a gatekeepers. The data collection was informed by an approach that emphasises the co-construction of meaning through participants' reflections and

interactions. This perspective recognises that knowledge is socially constructed and shaped by context, dialogue and lived experiences. When developing interview guidelines for Papers II and III, I drew on Lundy's model of participation to frame CYP's involvement. This model helped ensure that the discussions addressed CYP's right to express their views and have those views taken seriously. I also had Shier's (2001) dimensions in mind: openings, opportunities and obligations. In this context the guidelines introduced topics such as participants' experiences of working on research involving CYP's participation (Paper II), supporting researchers in gaining access to CYP for research purposes (Paper III) and their attitudes towards these subjects. Other topics included participants' understanding of childhood studies and definitions of vulnerable groups (Papers II and III), as well as workplace policies and knowledge regarding working methods (Paper III). In Paper II the participants were researchers working at the University of Iceland, who have experience of working on qualitative research with CYP and have experience of dealing with gatekeepers in the welfare system. In the interview guidelines the goal was to address researchers' experiences of applying for access to CYP and the challenges that come with it. In Paper III the data came from practitioners working in child protection services who have the role of gatekeepers when researchers want to involve CYP in research on CYP with experience of the child protection services. In the guidelines the goal was to address participants' personal experiences, views and reflections regarding their roles in facilitating research access, particularly when CYP were involved. In Paper II and III the format encouraged open dialogue rather than seeking definitive answers, in line with the qualitative nature of the study. Confidentiality was emphasised, and all data were anonymised to ensure that individual participants could not be identified. Participants retained the right to withdraw from the study within 30 days of the interview.

In Paper IV the data came from written notes in the form of wishes expressed by CYP who visited an art exhibition about children's rights, specifically related to violence and abuse. All elementary schools in Reykjavik with CYP aged 6–16 were invited to attend the exhibition with their teachers as part of their education on children's rights and discussions about the UNCRC. The exhibition was also open to the public, so a few wishes came from younger children as well. After viewing the artwork, CYP were offered time and a designated space to write down their wishes, thoughts and feelings in response to what they had seen. No further instructions were given to the CYP. Those who wanted to leave a message could place their notes in a box or hang them on a wish-tree.

3.3 Analysis of the data

The analysis in this thesis is both descriptive and interpretive. I applied reflexive thematic analysis as outlined by Braun and Clarke (2013), which is a method for identifying, analysing and interpreting patterns and themes within qualitative data. This

flexible approach allows for both semantic and latent level interpretation and is compatible with a constructivist epistemology, which underpins this study.

In Paper I the analysis of the data followed an iterative and reflective process, aligned with the six-stage framework for scoping reviews proposed by Arksey and O'Malley (2005). After developing inclusion criteria during the initial screening of abstracts, relevant articles were selected based on their alignment with the research aims. The included texts were subjected to a systematic coding process, through which recurring patterns were identified. These patterns informed the development of preliminary themes, which were subsequently refined in relation to the central research question and the overall objectives of the study. The process was both interpretive and analytical, involving continuous critical reflection. Final themes were synthesised and discussed to provide a comprehensive understanding of the key challenges researchers face when involving CYP in research.

The data in Papers II and III were gathered through semi-structured focus group interviews, which were recorded and transcribed. Thematic analysis was used to systematically explore the data, aiming to identify meaningful patterns related to the research questions. I began with open coding, examining both surface-level and underlying meanings to develop themes. Throughout the process, I engaged reflexively, acknowledging my own role in the interpretation and construction of meaning. I followed Braun and Clarke's (2013) six-phase process for thematic analysis, ensuring a systematic and rigorous approach to identifying patterns in the data. First, I familiarised myself with the data by reading it thoroughly and taking initial notes on recurring ideas and phrases relevant to the research questions. I then generated initial codes by manually identifying and labelling segments of text related to the subject matter (Papers II and III), choosing manual coding over software tools to maintain sensitivity to language and context. Each code was descriptively labelled to support clarity in subsequent analysis. Next, I organised the codes into broader categories, looking for commonalities, contradictions and emerging patterns. At this stage, I examined how participants' experiences and attitudes were reflected in the data. I then reviewed and refined the preliminary themes, ensuring they accurately represented the data across the full dataset. Overlapping themes were merged, weakly supported ones were discarded and key categories were sharpened to ensure clear boundaries while maintaining relevance to the research questions. Once the thematic structure was finalised, I defined and named each theme to capture its essence concisely. Themes were explicitly linked to the research questions and supported with direct excerpts from the data to illustrate their manifestation. Finally, I revisited the themes in relation to existing literature. The analysis process was iterative, allowing for continuous reflection and refinement to ensure the themes provided a deep, meaningful interpretation of the subject matter.

In Paper IV we also conducted a thematic analysis in accordance with Braun and Clarke's (2013) approach, coding the data/notes to identify and interpret key themes. It was decided to sharpen the CYP's perspectives by inviting three co-researchers, aged

16 to 17 and members of the Child Welfare Youth Council, to participate in the process by reviewing the data and contributing to coding decisions. Together, we developed descriptive and semantic codes, categorised emerging themes and applied inclusion criteria focused on messages relating to violence. The notes that were illegible or unrelated to the study were excluded. Using colour-coded post-it notes – one per note – we grouped similar codes and identified thematic patterns. Three themes emerged from the analysis, based on 630 notes from CYP. CYP's participation as co-researchers in this process was an informative and important experience, as it provided useful suggestions regarding the classification of codes and the naming of themes.

3.4 Ethical issues

The Icelandic Data Protection Authority had been informed of the project. Before each interview I clearly explained the study's aims and purpose. I then anonymised every piece of data. If any questions arose participants could contact me, the researcher. I also let them know I would transcribe the interviews and remove or alter all personal details.

Participants could leave the study, no questions asked, at any time up to 30 days after their interview or focus group meeting. I informed the participants of how I would use the data from the study, focusing on CYP's participation in research.

3.4.1 Ethics when involving children and young people in research

I placed ethical standards at the centre of this project, following the University of Iceland's Research Ethics Committee guidelines (2014), from start to finish. Although no children or young people were interviewed, one paper drew on pre-existing notes/wishes written by CYP (Paper IV). By the time I received these materials they contained no personal identifiers. The CYP were informed that their contributions would be examined and used, but I cannot assert with certainty that they were informed how the data would be used, particularly that it would form part of a research study. This raises important ethical considerations regarding informed consent when working with minors. The messages were anonymous and could not be traced back to individuals. Moreover, no record was kept of which CYP attended the exhibition, making it impossible to provide information about how their messages would be used. I considered these anonymous notes to be valuable data. Using them in a research context was a way of respecting CYP's contributions, and it was therefore decided to include them in the study. Regarding participants (Paper II and III), I clearly explained the purpose of the study, what participation involved and how their data would be handled, before obtaining written informed consent. Throughout the research process I engaged reflexively with these ethical issues, acknowledging my role and responsibilities as a researcher in safeguarding the dignity and rights of all participants.

4 Key findings from the research papers – a summary of the individual papers

This chapter presents the results of the four research papers included in the thesis. Each summary is structured to include the paper's aims and research questions, followed by relevant background information, a brief description of the data and the main findings. The focus is on how the key elements emerge through the analysis in each study.

Figure 1 presents the overall aim of the thesis and the titles of the four research papers. The figure illustrates how each paper contributes to the broader goal of increasing knowledge and understanding of how CYP can be supported to participate in social research. Each paper is introduced in the text that follows.

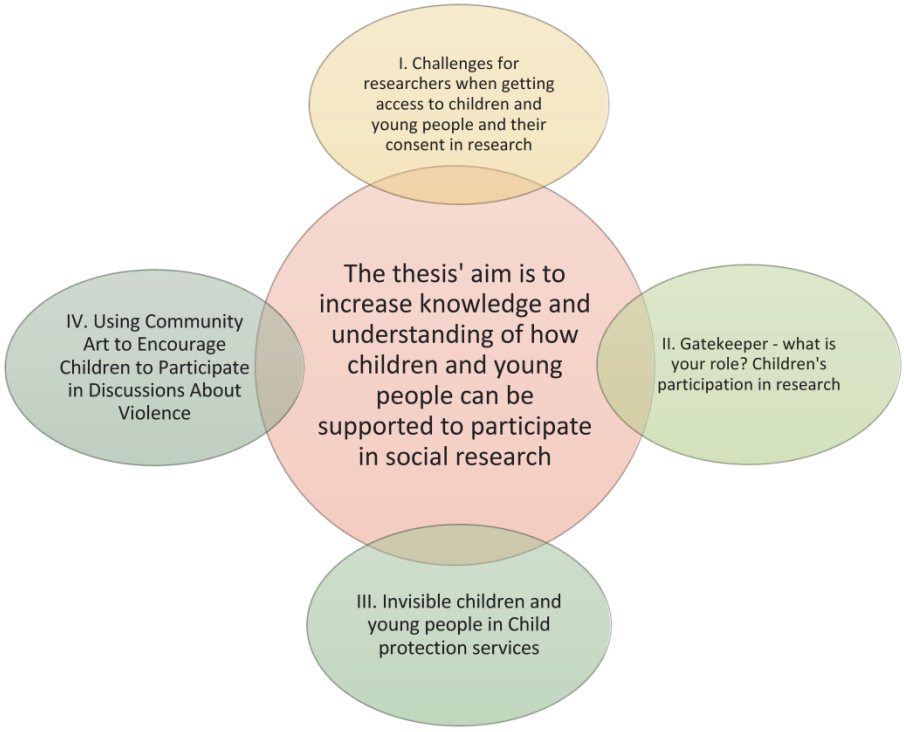

Figure 1. The aim of the thesis and the titles of the research papers.

As previously noted, three of the four papers are closely aligned in terms of their findings, while the fourth paper highlights the need for new and creative approaches to involving CYP in research. The first three papers discuss the challenges and obstacles researchers face in their interactions with gatekeepers, along with ideas for solutions to facilitate communication and increase the likelihood of gaining access to CYP. Paper IV is based on data where creative methods were used to support CYP's participation in the project. The paper concludes with recommending that researchers and others who interact with CYP adopt various approaches to involve CYP and support them in expressing themselves on sensitive issues, for example in research. In the fourth paper there is a discussion on how creative methods or approach, in this case, photographs and paintings, can be used to highlight and discuss violence against children with CYP in services and research.

4.1 Paper I: Challenges for researchers when getting access to children and young people and their consent in research. A scoping review

This paper aims to identify the challenges that researchers face when seeking access to CYP and getting their consent for participation in research. The research question framing the review is: What are the main challenges researchers must overcome when seeking access to CYP and getting their consent in welfare research? Despite the growing consensus about the need to involve CYP in research, there is a lack of literature on how to increase the participation of CYP in social research. Researchers have reported that seeking contact with CYP can be challenging, requiring approval from numerous gatekeepers.

To overcome the challenges in getting access to CYP and their consent in research, researchers should pay more attention to the concerns of gatekeepers and children. They should carefully prepare their studies to meet stakeholders' expectations and needs. By addressing these concerns explicitly through appropriate conduct and implementation of research processes, researchers can be more successful in involving CYP in research (Powell et al., 2018, 2020). Being creative and meaningful refers to how researchers can meet participants' needs by offering them choices regarding location and approach (Moore et al., 2018; Fleming, 2011). Researchers are responsible for using appropriate methods to ensure the study is in the CYP's best interests. CYP have emphasised that the research topics must be relevant and meaningful (Mossige & Backe-Hansen, 2013). Martins et al. (2018) and Kyritsi (2019) have presented ideas for a child-friendly interface and equipment to make the participation of CYP in research more meaningful for children. Using pictures and conversation cards has also proved useful (Guttormsdóttir & Kristinsdóttir, 2017; Woodhead & Faulkner, 2000). Building mutually trusting relationships and understanding includes beliefs, worries and perceptions of risk. From the researchers' point of view, the process stretching from the initial

application to getting access to CYP is often long and challenging. Contacting and getting buy-in from the gatekeeper is a difficult task for the researcher, sometimes resulting in the termination of the project (Daley, 2015). Previous studies relate that such processes have resulted in the exclusion of children and their voices (Carter, 2009; Cojocaru, 2013; Gallagher et al., 2012; Roose et al., 2009; Seim & Slettebø, 2017; Tunestveit et al., 2022).

Listening to stakeholders' demands and considering their concerns may increase researchers' likelihood of getting through the gates and asking CYP to participate (Daley, 2015; Graham & Powell, 2015; Moore et al., 2018; Powell et al., 2018; 2020).

4.2 Paper II: Gatekeeper – what is your role? Children's participation in research

This paper aims to shed light on the experiences of researchers in obtaining permissions, consent and access to CYP to involve them in research by discussing matters that concern them. We asked the following questions: What is the researchers' experiences in applying for permission to conduct research involving children? What is the researchers' experience in gaining access to children to request their participation in research? When conducting research involving children, researchers are required to obtain formal permissions from institutions, contracts from parents or guardians and assent from the CYP themselves. Access to CYP as participants often depends on the cooperation of institutions, professionals and guardians, collectively referred to as gatekeepers. These individuals play a crucial role in facilitating or restricting researchers' access to CYP.

The data come from two focus group interviews with working researchers at the University of Iceland. All the participants had conducted research involving CYP as direct participants and had considerable experience communicating with gatekeepers.

The findings indicate that there is a need to develop more effective ways to facilitate researchers' access to CYP while safeguarding their right to protection. Prolonged waits for permits and access should not deter researchers from involving children in research. Research indicates that CYP are willing and able to participate in studies under certain conditions, such as when the information is clear, the language and methods are appropriate and they believe that their participation will benefit others (Kristinsdóttir, 2017; Mossige & Backe-Hansen, 2013; Moore et al., 2018, 2021).

It is crucial for researchers to possess knowledge and experience of working with CYP and to create a safe environment for them. Our findings suggest that requirements for conducting this type of research need to be clarified. Additionally, the age limit for CYP participation in Iceland is 18 years. Researchers have criticised this and considered the age limit too high in this country (Kristinsdóttir, 1992; 2014).

Researchers, professional practitioners and policymakers need more dialogue on these issues, particularly regarding their responsibilities and roles in knowledge creation. Professional practitioners must become more aware of the importance of CYP's active participation in research. Moreover, a shift in attitude is necessary to move away from overly protectionist views and towards an approach that empowers CYP by providing them with opportunities to actively shape their own lives. With the expansion of research-oriented university education, it is anticipated that research literacy and methodological skills will improve. Although this alone will not resolve all challenges, it will contribute to a greater appreciation of the value of involvement and collaboration with CYP in research.

4.3 Paper III: Invisible children and young people in Child protection services

This paper aims to understand how practitioners in child protection services manage the balance between participation and protection and perceive their role as gatekeepers by addressing the following research questions: How do social workers balance participation and protection when supporting CYP's participation in research? How do social workers understand their role as gatekeepers? Arguments for CYP's participation in research are linked to the benefits for CYP who participate in research. Society's perspective has shifted from merely protecting CYP and shielding them from potential risks in research participation to also recognising their right to benefit from participation in research (Modi, 2020). The data were collected from 17 social workers in Iceland through five semi-structured focus group interviews.

The findings indicate that the participants generally recognised the importance of researching their services but did not view the direct participation of children as necessary. They argued that, due to the vulnerability of CYP in the service, participation in research would be overly complex and challenging for them. Instead, they suggested that researchers could gain insights into CYP's perspectives by reviewing available case files or secondary data already accessible from child protection services, or by speaking with adults who had previously received support from child protection services. This perspective suggests that the social workers prioritise a protective mindset, potentially at the expense of CYP's right to participate in research. The participants considered the CYP in child protection services particularly vulnerable and to often be living in challenging situations. Because of this, the additional pressure of participating in research could be difficult or even damaging. The participants expressed that being a gatekeeper should be a superior's role rather than the role of a practitioner working directly with CYP and their families. They mentioned several reasons for this. First, they do not have the time to complete these tasks because of heavy workloads. Second, contacting people and asking them for permission to participate in research could damage their working relationship with children and their families. It is crucial to balance respecting CYP's rights to participate in research and

ensuring their right to protection. Achieving this balance enables CYP to feel supported, recognised and included in decisions that affect their lives. To foster this balance, researchers must prioritise transparency and invest more time building trusting relationships with practitioners and other gatekeepers, demonstrating their knowledge, skills and experiences working among CYP. Additionally, researchers should explain how they will safeguard CYP's well-being during participation and ensure that the research outcomes benefit CYP both now and in the future.

When the emphasis on protection becomes too great in work with CYP, and their opportunities to participate in research are limited, they risk becoming invisible, their voices unheard and their experiences overlooked.

4.4 Paper IV: Using Community Art to Encourage Children to Participate in Discussions About Violence

Paper IV aims to present how an art exhibition may put children's experience of violence into focus and encourage attendees to reflect on the subject by looking at descriptive pictures and texts from the UNCRC and then writing comments about their thoughts and feelings by addressing the research questions: How do children express themselves about sensitive topics such as abuse and violence? Can community art enable professionals to better support the increased participation of children in discussions about abuse and violence?

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 art form that gives artists the opportunity to work in collaboration with the public, with the aim of highlighting and addressing specific social issues. The research data consisted of 1,751 notes written by children who attended the exhibition *Wishes of Icelandic Children*. Based on the number of wishes received from the children and how they described 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, in order to increase 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. Professional practitioners who work with children, like teachers and social

workers, could be trained to offer advice on sensitive issues using creative methods and then invite children to participate in solving the problems in their environment. Such solutions could be used in child welfare services and in school communities to improve children's lives and environments.

When analysing the findings from these four papers, four overarching subjects are prominent across Papers I, II and III: the balance between participation and protection; perceptions of safety and risk; the importance of researchers' competence; and the use of creative and child-centred methods. Although Paper IV approaches the topic from a different perspective, it contributes to the discussion on creative methodologies and shares overlapping concerns in terms of supporting CYP's expression and participation. Together, these studies highlight the challenges of involving CYP in research, while also pointing to practical strategies and innovations that can foster more inclusive research practices.

5 Discussion

This doctoral thesis aims to increase knowledge and understanding of how to support CYP in participating in social research on issues that concern them. In order to increase knowledge and understanding I have investigated three challenges researchers must be aware of and overcome when involving CYP in social research. The first challenge focuses on ethical and methodological challenges researchers must overcome to obtain the support of gatekeepers to gain access to CYP for participation in social research (Papers I, II and III). The next focuses on the practitioner's understanding of the practical implications of CYP's participation in social research (Papers I and III), and finally, how to adapt creative research methods to overcome methodological challenges in social research with CYP's participation (Papers I and IV). The research questions below were explored through the four papers included in this thesis:

1. What ethical and methodological challenges do researchers need to overcome in order to obtain support of gatekeepers to gain access to children and young people for participation in social research?

2. How do practitioners in child protection services understand the practical implications of children and young people's participation in social research?

3. How can research methods be adapted to overcome the challenges of involving children and young people in research?

The discussion draws on the papers (Papers I, II, III and IV) on which this thesis is based, reflecting on the findings, and through the theoretical framework of social constructionism, childhood studies and recognition theory.

The results reveal a complex and challenging process for researchers seeking access to CYP in vulnerable situations for research participation, leading to limited opportunities for CYP to participate in research. The challenges are primarily due to the gatekeepers' prevailing emphasis on protection at the expense of participation, and a lack of dialogue and mutual understanding between researchers and practitioners. These limitations are often linked to the challenges researchers face in gaining access to CYP for participation in social research and in navigating interactions with gatekeepers. Access applications must navigate a hierarchy of formal and informal gatekeepers responsible for safeguarding CYP's rights to protection and participation.

The following section will discuss these challenges in relation to the project's research questions.

5.1 Ethical and methodological challenges

The findings reveal significant ethical and methodological challenges, and at times even barriers, to involving CYP in social research. These challenges align with previous studies highlighting the complexities of including CYP in research (Daley, 2015; Powell et al., 2018, 2020).

5.1.1 Ethical challenges

Ethical challenges raised by both researchers and gatekeepers (Papers I, II and III) significantly limit opportunities for CYP to participate in social research. These challenges reflect practitioners' prioritisation of protecting CYP from harm and shielding them from external influences by researchers. There is also mistrust among practitioners who question whether researchers possess the necessary competence to ensure CYP's safety and whether they fully grasp the vulnerable position of these CYP and what is required to protect them.

In the findings (Papers I and II), researchers stated that they frequently encountered systemic challenges because gatekeepers often prioritised protection over participation, leading to delays, unclear decisions and the passing of access requests between multiple gatekeepers. This inertia reflected a dominant protectionist mindset and a distrust in CYP's competence to consent or decide on research participation. Even ethical approval from research committees appeared to have limited impact in facilitating. Researchers need to create time to strengthen their relationships with gatekeepers in order to gain their trust, as well as improve their ability to clearly articulate their competence (Paper I).

Practitioners (Papers III), on the other hand, were generally aware of CYP's rights to participation and made reference to the UNCRC. But they recognised their responsibility to protect CYP and viewed these two duties as incompatible when dealing with vulnerable CYP. Most practitioners were unwilling to ask CYP in the child protection system to take part in research and speak to unfamiliar researchers about their lives and said they were unable to assume that responsibility. They considered those CYP too vulnerable, particularly those in complex and precarious circumstances who were unwilling or unable to discuss their experiences in depth. To capture CYP's perspectives (Paper III), practitioners suggested that researchers use alternative, indirect methods, such as analysing case files or relying on adult narratives from those who had experience with child protection services.

These challenges appear rooted in traditional conceptions of childhood, which are grounded in developmental and age-based assumptions that view CYP as not yet competent. Such views stand in contrast to more contemporary understandings that recognise CYP as social agents shaped by their experiences and cultures (James et al., 2012; Corsaro, 2011). In practice, ideas about the social construction of childhood and

about CYP's rights and autonomy are both acknowledged and constrained, and are rarely translated into everyday professional practice. This ambivalence is evident in the way practitioners (Article III) claim to be aware of CYP's rights under the UNCRC (1989), yet tend to overprotect CYP in ways that may silence them and deprive them of opportunities to influence their own lives and circumstances (Daley, 2015; Fern, 2012; Garcia-Quiroga & Agoglia, 2020; Heimer et al., 2018; Kennan & Dolan, 2017).

This protectionist approach can silence CYP voices and wishes, as well as their understanding of their reality and experiences (Brady, Shaw & Blades, 2012; Carter, 2009; Kurt, 2022; Perry-Hazan, 2016; Stafford et al., 2021; UNCRC, 1989). These findings point to outdated views of childhood in which CYP are primarily seen as only "becomings" rather than also as "beings" (James et al., 2012). This reinforces paternalistic models that protect CYP from participation rather than supporting them to participate. As many scholars have argued (e.g. Daley, 2015; Fern, 2012; Garcia-Quiroga & Agoglia, 2020), excessive focus on protection without recognising the value of participation can marginalise CYP and lead to no participation, thus running the risk that CYP become invisible.

5.1.2 Methodological challenges

In addition to ethical concerns, several methodological challenges emerged (Papers I, II and III). These challenges are related to practitioners' perceptions of researchers' practical competence in communicating with CYP and ensuring their safety. They also concern researchers' inability to explain their qualifications clearly and understandably in their access applications. Additionally, a challenge lies in the limited ability of some researchers to use creative and child-centred methods when working with CYP.

Practitioners' attitudes were significantly shaped by their perceptions of researcher competence to communicate with CYP (Papers I, II and III). Researchers were often seen as outsiders who may lack the necessary communication skills, contextual knowledge or ethical sensitivity to engage CYP safely and meaningfully. Trust in researchers was closely linked to their ability to demonstrate appropriate safeguarding measures, articulate the value of participation and employ creative, child-centred methods. Practitioners discussed how researchers' procedures in their access applications were poorly designed, complex and illegible (Paper III). They therefore called on researchers in their access applications to provide clear, accessible research plans in their access applications that set out how research will be conducted, how CYP will be protected and what potential benefits participation may bring and why it is important to talk to a CYP instead of adults who have had the same experience. Researchers do not appear to agree that their research plans are unclear. They believe that their research plans are clear and address the key considerations required when CYP are involved, as evidenced by the fact that their studies have been approved by research ethics committees (Papers I and II).

Practitioners emphasised the importance of trust and that researchers take the time to visit the working place to introduce themselves and build relationships with the gatekeepers, which would be a prerequisite for granting access and allowing research to proceed (Paper III). For some researchers (Papers I and II), spending time – time they felt they did not have – on building relationships with gatekeepers proved frustrating. Practitioners indicate (Paper III) that access to sensitive CYP is not granted lightly and poorly managing the issues mentioned earlier can lead to tensions between protection and participation and results in participation being restricted rather than facilitated.

There is a methodological concern regarding whether researchers possess the tools, knowledge and confidence to offer CYP a meaningful choice in how they express themselves (Papers I and IV). Researcher competence, then, becomes a determining factor in both the willingness of practitioners to act as gatekeepers and the ability of CYP to participate meaningfully. When researchers clearly communicate their ethical commitments, show a sensitivity to risk and employ creative approaches that resonate with CYP's lived realities, they are more likely to secure practitioners' cooperation. As emphasised throughout this thesis, including in Papers I and IV, researcher trustworthiness is foundational to overcoming institutional and cultural barriers to participation.

These challenges are shaped both by institutional constraints that appear to be culturally embedded and by prevailing assumptions about researcher's inability to work with CYP (Daley, 2015). Scholars have underscored the importance of creative and flexible methods for engaging CYP, especially in institutional or restrictive environments (Papers I and IV). Participation in research should be less dependent on age and more on context, appropriate methods and support. In this context Shier (2001) and Moore et al. (2018) emphasise the need to provide CYP with genuine options for expression by inviting them to choose a method of expression, which is central to active participation.

The results indicate a need for ongoing professional development and retraining, as well as an ongoing discussion about contemporary understandings of childhood within welfare services and how to implement these ideas into action. There is a need for closer cooperation between researchers and practitioners when starting a new project.

5.2 Practitioners understanding of practical implications

The findings reveal several challenges with practical implications, including practitioners' attitudes, their role as gatekeepers, perceptions of researchers' ability and the limited integration of research into everyday practice.

Even though participants said they did not pay much attention to research findings in everyday work, they wanted to see more research on child welfare services and their

work as professional practitioners. Such research would then shed light on the importance of the work and for others to learn about the services.

In a discussion (Paper III) on how practitioners understood their role as gatekeepers being part of increasing diverse research in child protection, practitioners revealed that they did not see it as their responsibility to assist researchers with access and that this should not be their role. Finding the right participants would require a lot of time that they did not have, and they perceived it as an additional burden that could potentially strain their relationships with the CYP and families they worked with. Given this tension, several practitioners suggested that gatekeeping responsibilities might be better managed by institutional managers who do not have direct, ongoing involvement with the CYP and families concerned. This distancing reflects an underlying fear that offering CYP the possibility of participating in research might disrupt existing trust or add an emotional burden to already complex relationships. All the researchers (Papers II) had experience of working with CYP in welfare services earlier in their lives, prior to entering research, and reported encountering considerable mistrust from gatekeepers, who doubted their ability to work safely and competently with CYP. Due to such doubts and perceptions of researcher incompetence, the process of obtaining access was frequently prolonged, often beyond what was feasible for researchers, forcing them to find alternative routes for their projects. Some resorted to contacts at former workplaces or relied on practitioners they knew to gain access to CYP. They felt it was nearly impossible to gain access without personal connections with gatekeepers, posing particular challenges for early-career researchers lacking such networks. This resistance and the time-consuming nature of the process sometimes resulted in the research not being carried out at all, either because gatekeepers refused access or because researchers withdrew their applications due to delays.

Despite increasing demands within social services for professionals to be familiar with research findings to inform their work (Drisko & Grady, 2015; Guðmundsson & Árnadóttir, 2019; Perry-Hazan, 2016), practitioners did not generally appear to view it as a practical or necessary tool for improving decision-making or service development. This detachment from the research process may stem from a combination of institutional inertia and a lack of clarity about the relevance of academic research to frontline work (Gudjonsdottir et al., 2017). This may raise questions about how or if evidence-based approaches have been successfully implemented in professional practice (Drisko & Grady, 2015; Gudjonsdottir et al., 2017; Guðmundsson & Árnadóttir, 2019).

These findings highlight that the practitioners (Paper III) did not feel responsible for ensuring that researchers have access to CYP for research participation. It can therefore be concluded that to increase CYP's opportunities to participate in research, it is necessary to improve the research literacy of practitioners and increase practical training in the use of research in professional practice. When these conditions are met, practitioners may be more willing to support CYP's participation in research, thus

contributing to the wider realization of CYP's rights (Gallagher et al., 2012; Lundy, 2018; Tunestveit et al., 2022).

5.3 Adapting creative research methods to overcome challenges

This section highlights the role of creative and participatory methodologies in addressing the complex challenges associated with CYP's participation in research.

In the findings (Paper I), CYP expressed a clear preference for being able to choose how they communicate. They emphasised that researchers should be familiar with a variety of methods and offer flexible options. Some CYP preferred verbal expression, while others felt more comfortable using creative or non-verbal approaches, which enabled them to express difficult emotions or situations that were hard to put into words. They also noted that not all CYP appreciate creative methods – some may find them childish – highlighting the importance of choice and adaptability.

Papers I and IV demonstrate that creative approaches are both useful and ethically necessary for fostering meaningful engagement with CYP, particularly in sensitive contexts. Practical tools such as visual aids, conversation cards and flexible interview formats help create inclusive, child-friendly environments that recognise CYP's competencies and lived experiences. These methods support CYP's meaningful participation by offering multiple avenues for self-expression, thereby promoting agency and reducing reliance on traditional, adult-centric communication models.

Paper IV illustrates how artistic and participatory methods can cultivate safe, relational spaces where CYP feel empowered to explore difficult topics, including violence or others often surrounded by silence, stigma or fear. These symbolic and creative approaches allow CYP to engage on their own terms, offering a sense of control and safety in the research process. Rather than merely facilitating data collection, these methods embody ethical commitments to respect, trust and empowerment. They support CYP in sharing valuable insights and ensure that participation is not only possible but also meaningful and beneficial.

These approaches align with contemporary perspectives in childhood studies, which view CYP's agency as relational and materially situated, shaped by their environments, relationships and modes of communication (Mannion, 2007; Spyrou, 2019). Adopting co-productive methodologies, as advocated by Tisdall (2017), enables researchers to treat CYP with respect as active co-constructors of knowledge, enhancing both ethical integrity and the validity of findings.

Despite these promising strategies, structural and institutional challenges persist. Access to CYP in regulated settings, such as child protection services, continues to be restricted by adult-centric norms and risk-averse gatekeeping. The findings (Papers I and IV) suggest that these challenges can be mitigated by frameworks that can support researchers in accessing CYP and create enabling environments for participation. The model proposed by Bouma et al. (2018) provides a valuable ethical and relational

framework for supporting meaningful participation of CYP in research in sensitive and regulated contexts. Emphasising key principles such as respect, transparency, negotiation and attention to context, it aligns closely with participation models like those of Lundy (2007) and Shier (2001), which conceptualise participation as a continuous and dynamic process. All three models emphasise the importance of involving CYP from the earliest stages, including the identification of relevant issues. These frame CYP as active contributors and stress the importance of embedding their input into real and consequential processes. Bouma et al.'s (2018) focus on relationship building as a basis of necessary trust and ethical integrity offers a practical strategy to address gatekeepers' concerns around CYP's safety and researcher competence. By demonstrating transparency, respect and commitment to ethical collaboration, researchers can build trust with gatekeepers, facilitating access to CYP while upholding CYP's rights and agency.

This thesis contributes to understanding how CYP living in challenging situations can be supported to participate ethically and meaningfully in research. While creative methodologies may offer inclusive tools for all CYP, this study highlights their particular value in overcoming challenges that may hinder the participation of CYP in child protection or other marginalised settings. Building on this foundation, adapting creative and participatory research methods represent not only a methodological necessity but also an ethical opportunity to empower CYP and respect their diverse ways of communicating. Approaches such as visual tools, participatory art, storytelling and flexible interview formats create inclusive and responsive environments where CYP can express themselves safely and meaningfully. These methods challenge outdated notions of childhood as a period of incompetence, recognising instead a phase rich in agency, connection and meaning-making (Andrews, 2012; Dunk-West, 2013). For researchers, integrating creative methods can enhance access to CYP, foster trust and cultivate ethical research environments where CYP's voices are genuinely respected and their participation truly supported.

5.4 Limitations

A few limitations should be kept in mind when interpreting the findings. The generalisability is limited by the fact that they reflect the personal experiences and perspectives of the participants involved. In some cases, particularly in Paper IV, the decontextualised nature of the data made interpretation challenging. Participants had varying levels of relevant experience (Paper II and III), which may raise questions about the suitability of the target group. In Paper III the data collection period spanned five years due to the COVID-19 pandemic, potentially influencing the consistency and scope of the findings. Finally, practical constraints, including restricted access to visitor information (Paper IV), limited the depth of analysis. Despite these limitations, the studies offer valuable insights into CYP's participation in research.

6 Conclusions

This thesis contributes to new understanding to the field of childhood studies and ethical research by illuminating the complex interplay between protection and participation in research involving CYP living in challenging social environments. By examining the ethical, methodological and practical implications of CYP participation in social research, particularly in sensitive settings such as child protection services, the findings challenge prevailing assumptions about CYP's capacity, competence and rights to be heard.

A key contribution lies in highlighting the tensions between adult-centric protectionist frameworks and children's rights to meaningful participation. Although practitioners and researchers often acknowledge CYP as rights-holders and capable participants, this recognition is inconsistently applied. Ethical concerns, institutional gatekeeping, and a pervasive fear of doing harm frequently override opportunities for CYP to speak for themselves and participate in decisions. The thesis reveals how such barriers are rooted in outdated conceptions of childhood, which still frame CYP as passive, vulnerable beings rather than as active social agents.

What is particularly novel in this research is the detailed analysis of how creative and participatory methods, including art, visual tools and adaptable interviewing can enable CYP to reflect deeply and safely on sensitive issues. These approaches not only enhance the ethical quality of the research process but also demonstrate that CYP are capable of engaging meaningfully when provided with appropriate conditions, support and respect. By shifting focus from developmental limitations to relational and contextual strengths, this thesis supports a reconceptualisation of CYP not only as "becomings" but also as knowledgeable "beings" with valuable insights.

The thesis uncovers an important disconnect between practitioner discourse and practice. While practitioners understand the principles of CYP's rights, they often lack the structural support, time or trust in researchers to operationalise these principles in everyday decision-making. Researchers need to take the time to build relationships to create trust with gatekeepers by investing time in dialogue, trust-building and transparency around ethics and intentions. Researchers need to use time to introduce themselves and their work and to seek to understand gatekeepers' concerns. This points to a need for institutional and cultural change beyond individual attitudes, towards a research climate that genuinely embraces CYP's participation as a right, not a risk. It demands a shift in institutional practices, researcher competence and methodological imagination. When CYP are engaged as active participants using creative, flexible and ethically sound methods, their perspectives can inform and transform both research and

the services designed to support them. This research thus contributes to the broader realisation of CYP's rights, enhancing both the quality of research and the responsiveness of welfare systems to the lived realities of CYP.

In the Icelandic context, these insights have practical implications. CYP involved in child protection services are frequently excluded from research, thus silencing their voices and diminishing their capacity to influence the very systems meant to support them. Addressing these challenges requires more than ethical awareness; it calls for attitudinal and structural shifts that recognise CYP as competent individuals and active citizens. Only by embedding participation in everyday research and practice can we begin to build systems that truly reflect the realities, rights and aspirations of CYP.

7 Implications for researchers

If research aims to understand the lives and experiences of CYP, it is essential that they are actively involved as participants, not just spoken for by adults. Researchers have been criticised for interviewing adults about their experiences of childhood, instead of seeking information directly from CYP about their experiences and opinions in their present time (Fern, 2008; Litt, 2003; Kellett, 2010; 2011).

Figure 2 below presents strategies that may help researchers achieve better outcomes in research with CYP, particularly when linking participation to mutual recognition in line with Honneth's (1995) forms of recognition. In order to develop strategies that enable researchers to overcome the challenges they face when gaining access to CYP's participation in social research, researchers should have the four overarching subjects

in mind in accordance with the results of this study:

Figure 2. Strategies that enable researchers to overcome challenges in research with CYP.

Participation & protection:

- Work collaboratively with practitioners to shift perceptions from protection to empowerment.
- Consider Shier's (2019) model of child participation and aim to move towards "children's direct decision-making" where appropriate.
- Ensure CYP feel safe, respected and valued and can see how their contributions may lead to a real impact on their own life or that of others in similar situations.
- Support gatekeepers to understand the value of CYP participation in research and how it can inform better services.
- Offer training and clear frameworks to support gatekeepers in seeing participation not as a risk but as a means of empowerment.

Relationships & trust:

- Build relationships with gatekeepers by investing time in dialogue, trust-building and transparency around ethics and intentions.
- Consider Honneth's theory (1995) and link participation to mutual recognition when establishing trust by involving CYP in decisions about the research process, including how and when they participate.
- Invite practitioners/gatekeepers into the research process to bridge gaps between research and practice.

Safety & risk:

- Be explicit about ethical safeguards and continually reflect on how to maintain ethical integrity throughout the process.
- Choose a place in cooperation with CYP to increase the feeling of a safe space.

Researcher competencies & creative approaches:

- Continuously develop as a researcher, methodologically and ethically.
- Embrace innovation and creativity in research design, always centring the needs and voices of CYP.

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Challenges for researchers when getting access to children and young people and their consent in research. A scoping review

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ABSTRACT

This article aims to support researchers in addressing the challenges when seeking access to CYP and their consent to participate in research. Despite the growing consensus about the need to involve children and young people in research, there is a lack of literature on how to increase their participation in welfare research. Researchers have reported that seeking contact with children and young people can be challenging, requiring approval from numerous gatekeepers. This scoping review discusses challenges researchers must address when seeking access to children and young people and getting their consent for research. The article reports on findings from 14 qualitative studies, using thematic analysis to identify common topics. We conclude that the main challenges are a lack of clarity and confidence in researchers' communications with gatekeepers, children, and young people. To overcome those challenges, researchers should write clear research plans, demonstrate and clarify that they are qualified to work with children and young people and incorporate time for trust-building. However, we also conclude that more evidence from children's and young people's perspectives is needed to shed better light on their experiences participating in welfare research and what motivates them to agree to participate.

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Introduction

There has been growing awareness about children's rights and the importance of participation of children and young people [CYP] in research projects (Bradbury-Jones, Isham, and Taylor 2018; Carter 2009; Stafford et al. 2021; UNCRC 1989). Three approaches have been used to identify the level of CYP´s participation in research: Research *on* children, *with* children, and *by* children (Asselin and Doiron 2016). Clavering and McLaughlin (2010) describe cooperative research as being conducted *with* or *by* participants rather than *to*, *about* or *for* them. Research with CYP should use a rights-based approach (Bessell 2015; Colling 2012) that recognizes CYP's vulnerability and lack of power. It should also respect CYP's entitlement to express opinions about their lives and environment. Using a rights-based approach, researchers employ theories that authorize CYP to actively represent their perceptions of issues in their lives using child-friendly participatory methods, including drawing, talking, photographs, and making crafts (Bessell 2015; Colling 2012; Farmer and Cepin 2015; Guttormsdóttir and Kristinsdottir 2017). Even though research *with* CYP has increased, there is still a gap in research on the participation of CYP who are getting support from the child welfare system (Cojocaru 2013; Fleming 2011; Garcia-Quiroga and Agoglia 2020;

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Horwath 2011; Mossige and Backe-Hansen 2013; Perry-Hazan 2016). To produce research findings that are helpful in developing services in professional social and health practice (Drisko and Grady 2015), it is essential to have data from all groups of people, including CYP (Kennan, Fives, and Canavan 2012; Kiili, Moilanen, and Larkins 2023; Seim and Slettebø 2017; Stabler and Carro 2020). CYP are not a homogenous group; they have diverse needs and expectations (Arnadottir and Olafsdottir 2019; Merkel- Holguin et al. 2020; Stabler and Carro 2020). By recognizing CYP and supporting their participation in research, researchers can give CYP new experiences and an increased understanding of their rights (Kiili, Moilanen, and Larkins 2023).

Ethical standards that encourage trust and fairness are required in research involving CYP. Legal regulations differ between countries and sometimes even between ethical committees inside each country. The same applies to regulations regarding age limits for children's consent to participation. In any case, the researcher needs to follow specific standards to ensure the quality of the research (European Commission 2021; Kristinsdottir 2020; Peart and Holdaway 2000). After getting the required formal permission from the ethics committee, researchers need to get clearance regarding access to the target group.

Recruiting CYP receiving support from child welfare services for research projects is often challenging (Merkel- Holguin et al. 2020; Watson, Meineck, and Lancaster 2018) and sometimes results in failure to conduct the research project with the target group. On closer inspection, challenges for the researchers can often be found in their relationship with gatekeepers (Kennan, Fives, and Canavan 2012), who sometimes are called *betweeners* due to their position of being in between the data collectors and potential participants (Heath et al. 2007; Keesling 2011). Based on their personal or work position, gatekeepers can control who has access to the respondent and when (Keesling 2011; Powell and Smith 2009). They include managers and practitioners in welfare organizations and parents/caregivers (Kennan, Fives, and Canavan 2012; Kristinsdottir and Arnadottir 2015). Gatekeepers want to be included in the creation of the research plan early to ensure that it will be appropriate for CYP to participate in the research project (Reeves 2010; Skelton 2008).

Researchers depend on the gatekeepers' time and interest in paving the way to access children. However, the process is obstacle-oriented, leaving some CYP out of having a say in their participation in research (Checkoway 2011; Dentith, Measor, and O'Malley 2009; Fitzgerald and Graham 2011; Garcia-Quiroga and Agoglia 2020). In addition, researchers believe that gatekeepers find it challenging to balance participation and protection because they do not recognize these concepts as cohesive; instead, they see them as conflicting forces (Dempsey et al. 2016; Sandberg 2018; Vis, Holtan, and Thomas 2012). This challenge could lead to the exclusion of CYP in favour of adult participants (Schelbe et al. 2014; Tunestveit, Njøs, and Seim 2022) and failure to include CYP's voices (Carter 2009). The outcome is that researchers adhere to protective ideas about CYP instead of looking at their skills, competencies, and their right to have to say about their lives and sometimes the lives of others (Cojocaru 2013; Fitzgerald and Graham 2011; Gallagher et al. 2012; Roose et al. 2009; Seim and Slettebø 2017).

In this review, we point out factors that researchers need to explain better when requesting access to children to increase the likelihood of obtaining consent from all stakeholders. We aim to support researchers in addressing the challenges when seeking access to CYP to participate in research. The purpose is to enhance opportunities for CYP to be involved. Thus, the research question framing the review is: What are the main challenges researchers must overcome when seeking access to CYP and getting their consent in welfare research?

Methods and analysis

In the research methodology literature, it is increasingly common to distinguish between the systematic review and the scoping review approach (Munn et al. 2018). The former usually produces a synthesized answer to a specific problem and may aim to provide best

practice guidance based on the sum of evidence. The scoping review approach, on the other hand, serves different purposes, including identifying the types of evidence available, examining how research is conducted on a particular topic, or identifying gaps in the knowledge base. In this study, we chose a scoping review to map relevant articles and address the current knowledge about challenges researchers face when seeking access to CYP for welfare research.

Sampling criteria

In this review, we chose research articles carried out *with* CYP in welfare research. The focus is on 10–18-year-old CYP because this literature review is part of a larger project where the age limit is 10–18 years. We conducted the searches in Scopus and ProQuest. We used the following keywords for the search: 'qualitative research' or 'social research', 'youth or 'children & youth', 'research participation' or 'participation in research' or 'involvement', 'children's involvement' or 'children's participation'. The entire search string is available from the first author upon request.
We included articles if:

- they were related to issues arising when seeking access to CYP and their consent, aged 10-18,
- they included researchers' reflections about conducting qualitative research with CYP,
- they were published in English or Icelandic journals between 2015 and 2021,
- full access was attainable,
- the study context was related to research within child welfare services,
- they were scientific peer-reviewed publications.

We excluded articles if:

- the research focused primarily on children younger than 10,
- they concerned adults, 18 years and older,
- the topic was research conducted *by* CYP,
- the study addressed only methodological issues,
- they were review studies.

The process of selecting the final articles for analysis was a reflective journey. First, the research team read through the articles' full texts and discussed the relevance of the material. The review includes 14 articles with stakeholders: CYP, gatekeepers, and researchers. As shown in Figure 1, the search and retrieval process identified 1163 studies through the initial search process. We read 44 studies in full text to determine if the inclusion criteria were met; this eventually led to the exclusion of 30 of those studies. Later, we identified 12 additional articles by looking for other potentially relevant articles in the reference lists of the previously identified articles and by consulting with colleagues who are experts in the field. We excluded 12 of the remaining studies because they focused on child led projects. Thus, the final sample included in this review is 14 articles.

Analysis

To ensure that the literature is covered and to analyse the findings, we adopted the five stages framework from Arksey and O'Malley (2005) which describes the process from the research question to the discussion. The process is not linear but interactive, requiring reflective thought at every step of the writing process. After creating a research question, we identified keywords to search for relevant studies. Then, reading abstracts, we generated criteria for deciding which upcoming articles suited the research´s aim and purpose. Our analysis process was interactive. We read and coded the text, looking for 'bottom-up' patterns and building themes related to the

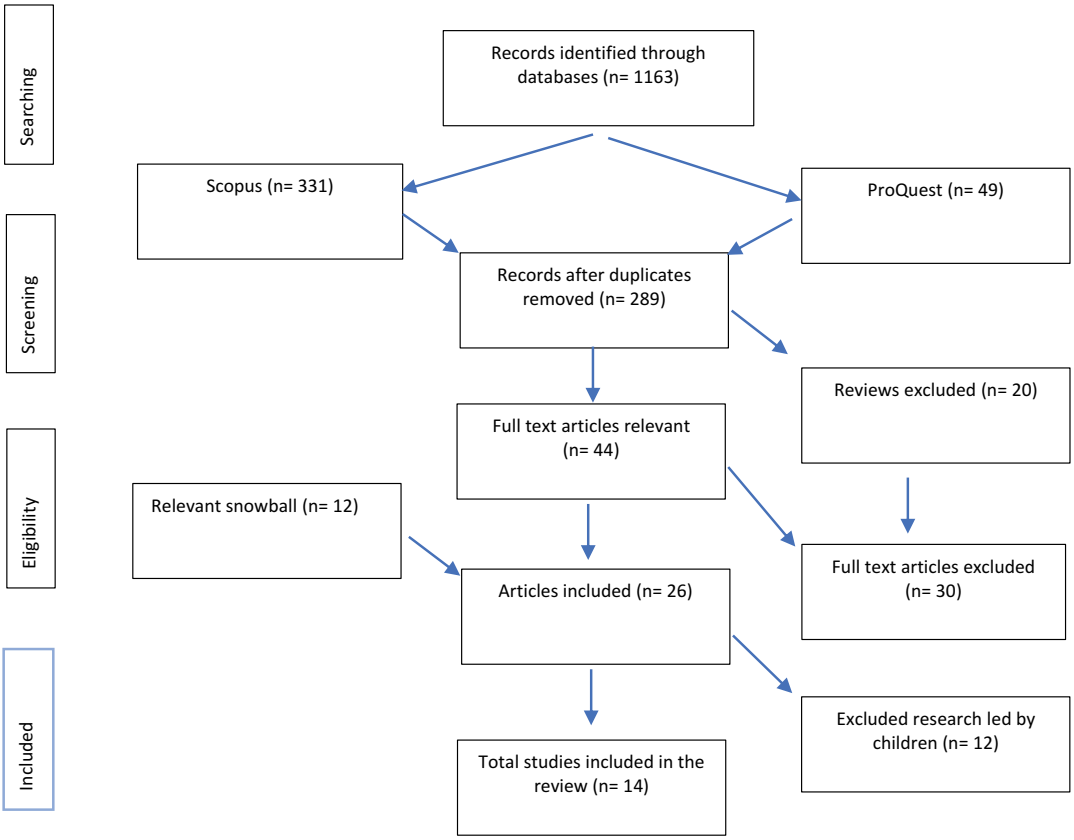

Figure 1. Flowchart of literature search and selection process.

research question and the project's aim. Reading and coding the text led to the themes we present and discuss in this article.

Findings

The 14 articles address the subject of research with CYP differently; some are self-reflections about previous studies, while others use individual or focus group interviews with stakeholders, including CYP and gatekeepers. The included studies were conducted in the Minority world: Australia ($n = 7$), England ($n = 2$), New Zealand ($n = 1$), New Zealand and Australia ($n = 1$), Scotland ($n = 1$), Ireland ($n = 1$), and Portugal ($n = 1$). None of the included articles came from the Majority world as defined by Tisdall and Punch (2012).

Analysis of the articles resulted in three main topics: (1) The researchers´ competences, (2) The research project, and (3) Understanding and trust.

Five of the fourteen articles address the gatekeepers' and CYP's concerns about the reputation and qualifications of the researchers when deciding if they want to support the project and participate in the research (Martins, Oliveira, and Tendais 2018; Moore, McArthur, and Noble-Carr 2018; Moore et al. 2021; Powell et al. 2018, 2020). To support research and open the gates, stakeholders want researchers to be more precise about the following themes: the researchers' background and qualifications.

Table 1. Key characteristics of the included studies characteristics in table 1: 1. The researchers' competences. 2: the research project. 3: understanding and trust.

Author and year	Country	Study design	Main topic	Characteristics
Moore et al. (2021)	Australia	Focus group interview with children 9–16 years old	What factors lead children to agree to participate in social research? Extrinsic and intrinsic motivations for participation.	1.The researchers' competences 2. The research project 3. Understanding and trust
Powell et al. (2020)	Australia	Semi-structured interviews with 42 adult and child stakeholders	Address and explore factors that influence decision-making from the stakeholders' point-of-view.	1.The researchers' competences 3. Understanding and trust
Kyritsi (2019)	Scotland	Case study	How to obtain ongoing and informed consent in research with children.	2. The research project 3. Understanding and trust
Moore et al. (2018)	Australia	Case study	How to be creative and use pictures when choosing methods for research with children.	1.The researchers' competences 2. The research project 3. Understanding and trust
Vaswani (2018)	England	Case study	Reflection on researchers' obstacles in seeking children's participation and discussing how to overcome these obstacles.	1.The researchers' competences 3. Understanding and trust
Martins et al. (2018)	Portugal	Case study	How to obtain informed consent using plain and meaningful language.	1.The researchers' competences 2. The research project 3. Understanding and trust
Powell et al. (2018)	Australia	Interviews with children, parents, and other stakeholders	Stakeholders' perspectives on what is defined as a sensitive topic to help address a potential concern and facilitate the development of research with children.	1.The researchers' competences 2. The research project 3. Understanding and trust
Kennan and Dolan (2017)	Ireland	Case study	The challenge of navigating the balance between participation and protection.	3. Understanding and trust
Turner and Almack (2017)	England	Case study	Exploration of complexities of relationships and negotiations with gatekeepers.	3. Understanding and trust

(*Continued*)

Table 1. (Continued).

Author and year	Country	Study design	Main topic	Characteristics
Powell et al. (2016)	New Zealand/ Australia	Case study	How to improve practice in qualitative research involving children.	3. Understanding and trust
Collings et al. (2016)	Australia	Case study	To balance and be aware of the tension between parents' and children´s rights.	3. Understanding and trust
Moore et al. (2016)	Australia	Case study	How to use reference groups made up of children to promote and help researchers reconsider their research approaches.	2. The research project 3. Understanding and trust
Daley (2015)	Australia	Case study	Balancing protection and participation in research design.	3. Understanding and trust
Graham and Powell (2015)	New Zealand	Case study	How to provide a framework for approaching ethical research involving children.	3. Understanding and trust

The researchers' competences.

Researchers' background

The researchers' responsibility is to provide all stakeholders, professionals, parents/caregivers, and CYP with enough information to decide whether they want to support the researcher's project by participating (Moore, McArthur, and Noble-Carr 2018; Powell et al. 2018). Moore et al. (2021) and Powell et al. (2020) point out that, from the point of view of the gatekeepers, it is essential that researchers give information about the institution they represent. They emphasize that gatekeepers trust researchers who represent universities more than those representing other agents, like non-governmental organizations. The challenge for researchers is demonstrating the institution's quality and developing genuine respect and trust.

Researchers' qualifications

Moore et al. (2021) and Powell et al. (2020) address the requirements from stakeholders about the quality and experience of researchers working among CYP. In general, researchers must present themselves and their work in a way that demonstrates their ability to work professionally with CYP. For instance, researchers must demonstrate their relevant educational and experiential background for working with CYP. The challenges entail establishing trust and cooperation with CYP. Furthermore, researchers should be capable of informing gatekeepers that they are skilled in various methods when working with CYP and emphasize how they consider their approaches according to age, developmental stage, and cultural background (Martins, Oliveira, and Tendais 2018; Moore, McArthur, and Noble-Carr 2018; Moore et al. 2021; Powell et al. 2018, 2020). Informed and meaningful participation is a critical aspect of research with children and young people (Martins, Oliveira, and Tendais 2018). Therefore, researchers must provide information to ensure that CYP are fully informed and can freely give or withhold their consent (Vaswani 2018). They must explain to CYP the aims and purpose of the research and how findings will impact their lives both now and possibly in the future (Moore, McArthur, and Noble-Carr 2018; Powell et al. 2018). Moore et al. (2018) pointed out that researchers too often talk to CYP in complex language, which could lead to CYP not understanding the nature of their involvement in the project (Powell et al. 2020).

The research projects

Five articles describe how, for gatekeepers to be willing to encourage CYP to participate in research, researchers must show that they have chosen creative research design and methods appropriate for children (Kyritsi 2019; Martins, Oliveira, and Tendais 2018; Moore, McArthur, and Noble-Carr 2018; Moore et al. 2021; Powell et al. 2018).

Creative and meaningful

CYP have expressed their desire to choose whether to participate when asked to contribute or participate in a project. They want to have a say in the time and location of the meeting and whether they will be interviewed alone or in a group (Moore, McArthur, and Noble-Carr 2018). CYP were more likely to participate if the research issues were related to their daily lives and if the topics were well-known and meaningful. To have a chance to talk about things during the interview and 'get things off your chest' could be healing. Some CYP said it might be better to use face-to-face interviews rather than talking in groups if the topics are sensitive (Moore et al. 2021). Others disagreed, saying they would benefit from being in a group, allowing them to listen to the opinions of other CYP who have had similar experiences (Moore, McArthur, and Noble-Carr 2018).

CYP were less likely to participate if they did not connect to the subject or found it boring (Moore et al. 2021). While some of the reviewed studies seem to compensate for this by attempting to make the research process more 'fun for children', this can detract from the

purpose of the research (Moore et al. 2021; Moore, Noble-Carr, and McArthur 2016). CYP also reported wanting to know about the potential use of the project. All stakeholders would be more likely to support or participate in a study if they thought it would improve the lives of others (Moore et al. 2021; Moore, McArthur, and Noble-Carr 2018). Moore et al. (2018) and Kyritsi (2019) emphasize consent as part of an ongoing creative process rather than a unique event by including CYP in every research stage. CYP must understand what the researchers expect from them in the research process, which helps them know what they consent to (Martins, Oliveira, and Tendais 2018; Moore et al. 2021; Moore, McArthur, and Noble-Carr 2018). In discussing informed consent, Kyritsi (2019) criticized the process of seeking consent regarding participation in research, questioning whether CYP could exercise their fundamental rights when they are the last ones to be asked to participate. She argues that due to this low priority, CYP are powerless, and she questions whether they get to have a voice.

Understanding and trust

Twelve articles discussed gatekeepers' requests for building relationships to work on mutual trust and understanding of the subject and the importance of the research.

It is challenging for all actors to have time and space for reflective discussion about the meaning of CYP participation and protection with that aim to build mutual understanding of the aim and the purpose of the research and trust.

Gatekeepers' beliefs and worries

Six of the included articles discuss challenges related to gatekeepers' beliefs and worries about CYP's participation in research (Daley 2015; Graham and Powell 2015; Moore, McArthur, and Noble-Carr 2018; Powell et al. 2016, 2020; Vaswani 2018). Although we identified certain common factors in the articles, we found that gatekeepers' concerns varied based on their beliefs, roles, and experience working with CYP (Powell et al. 2020). After obtaining ethical clearance, researchers must negotiate with other gatekeepers, who are often overloaded with work and only sometimes prioritize researchers' applications to recruit participants (Moore, McArthur, and Noble-Carr 2018). This process has proven challenging and described as protracted, intricate, complicated, and sometimes unworkable for researchers (Vaswani 2018). Moore et al. (2021) discuss doubts among gatekeepers about whether it is always appropriate to ask CYP to participate in research because of their vulnerability and level of maturity. They question if it is appropriate to ask CYP to discuss sensitive topics, including sexual abuse, problems at home, or death. Other studies found that gatekeepers believe CYP can discuss every topic – it just depends on the researchers' qualifications and ability to use suitable approaches and tools. The researcher must contextualize participation appropriately related to CYP's development (Kyritsi 2019; Powell et al. 2020; Vaswani 2018). However, professionals are aware of the gatekeeper's role and the responsibility that comes with it because of children's rights to participate and have their voices heard (Powell et al. 2020). Researchers have noted that some gatekeepers believe that supporting researchers in accessing CYP goes beyond their professional responsibility (Collings, Grace, and Llewelly 2016).

Perception of risk

Eight articles discuss the gatekeepers' concerns about the risk of involving CYP in research as a crucial challenge (Collings, Grace, and Llewelly 2016; Daley 2015; Kennan and Dolan 2017; Kyritsi 2019; Martins, Oliveira, and Tendais 2018; Moore et al. 2021; Powell et al. 2020; Vaswani 2018).

Powell et al. (2020) discuss risk as a critical concern for gatekeepers and underline how researchers need to know how to plan and manage CYP's safety, including the potential impacts of the research. Under some circumstances, participation could traumatize CYP or jeopardize their safety. Daley (2015) and Powell et al. (2020) discuss a tension between respecting CYP's autonomy and the right to participate while protecting them from harm. Powell et al. (2020) found that

whether the research project should be supported was based on potential risks to the child, emphasizing how researchers acted to mitigate these. When discussing the importance of involving diverse groups in research, Daley (2015) argued that excluding people from participation in research can only be justified where there may be potential harm to participants. Daley (2015) discusses that ethical research reviewers are so preoccupied with protecting CYP from risks and harm that they compromise their rights to participate in research and have a voice in matters that affect them. Daley argues that excluding CYP from participation in research will lead to a lack of understanding of how CYP experience their lives and the provided services.

Thus, a protective attitude could result in CYP not being allowed to participate in matters that influence their own lives and environment. Collings et al. (2016) discuss parents' duty to protect their children versus the right of the latter to participate in research. In addition to preventing CYP from suffering emotional harm in research settings, researchers must create a safe and protective physical environment (Martins, Oliveira, and Tendais 2018). According to Moore et al. (2021), some CYP identified schools as safe places for interviews because these familiar environments could empower them and put them in an equal position.

Building relationships

Nine articles discuss the importance of establishing and maintaining good relations with gatekeepers (Collings, Grace, and Llewelly 2016; Martins, Oliveira, and Tendais 2018; Moore, McArthur, and Noble-Carr 2018; Moore et al. 2021; Powell et al. 2016, 2018, 2020; Turner and Almack 2017; Vaswani 2018). When gaining access to CYP and getting them to participate in research, researchers are often grounded in their competence to develop and maintain relationships with the key actors, gatekeepers, and CYP (Turner and Almack 2017). To the gatekeepers, it was essential to have the opportunity to form relationships with researchers (Moore et al. 2021; Powell et al. 2018), but for some researchers, building these relationships has proven frustrating (Martins, Oliveira, and Tendais 2018; Powell et al. 2020; Turner and Almack 2017). The relationships with gatekeepers give researchers opportunities to present the purpose, potential benefits, context, and details about the conduct of the study (Collings, Grace, and Llewelly 2016). As mentioned earlier, researchers need to share whether they know about CYP's cognitive level and have experience talking to children and young people in a language they understand (Powell et al. 2020; Vaswani 2018). Parents emphasized the importance of relationships with the researcher who would be in contact with their child. In some cases, the researcher's gender was relevant – for example, if the research were about sexual violence (Powell et al. 2020). Some CYP underlined trust and experience because they felt they would be more likely to agree to participate if the researcher had experience working with children and youth, which would increase their trust. Other CYP value the anonymity of an interview with a researcher they did not know before (Moore et al. 2021). Powell et al. (2020) discuss what effect the gatekeepers' relationships with CYP may have on CYP's decision to participate in research. They point out that CYP may not want to participate but feel obliged to because of their relationship with the gatekeeper. From CYP's perspective, this could be the case because of their position at school as class representatives or of loyalty, i.e. because someone they have a relationship with asked them to take part, and they could not refuse (Moore, McArthur, and Noble-Carr 2018).

Discussion

This scoping review aimed to support researchers in addressing the challenges when seeking access to CYP and their consent to participate in research. Our purpose has been to enhance opportunities for CYP to be involved in research. The research question was: What are the main challenges researchers must overcome when seeking access to CYP and getting their consent in welfare research?

Overall, this review requires ongoing development and analysis of best practices when conducting research with CYP to meet legal rights and the growing requirements regarding CYP in research (Bradbury-Jones, Isham, and Taylor 2018; Carter 2009; Stafford et al. 2021; UNCRC 1989).

We have divided the discussion into three main topics: The researchers' competencies and the research project itself (including the need to be creative and meaningful). The third topic concerns challenges such as understanding and trust, including beliefs and worries, perceptions of risk, and building trust and relationships. The discussion addresses each topic and presents ideas about overcoming challenges.

Six of the fourteen articles discuss researchers' competencies and challenges (Martins, Oliveira, and Tendais 2018; Moore, McArthur, and Noble-Carr 2018; Moore et al. 2021; Powell et al. 2018, 2020; Vaswani 2018). In addition, Moore et al. (2021) and Powell et al. (2020) discuss the importance of all stakeholders trusting the researchers' affiliated institution. Improving an institution's reputation would be a long-term task that would depend on factors including the institution's size and the researcher's level of influence. However, being part of or associated with a university will enhance trust.

When researchers seek the support of gatekeepers to access CYP and their consent, they must present their qualifications, knowledge and experience working with children.

Even if the researcher has appropriate approval from an ethical board, this does not necessarily guarantee access. Other gatekeepers may want to consider if the researcher is qualified enough. The gatekeeper's personal and professional values also impact the standards for such consideration. Vis et al. (2012) mention that gatekeepers have criticized researchers for lack of knowledge and experience when working with CYP in complicated situations. Gatekeepers have also criticized researchers for writing complex and lengthy introductions to their research plans, making it difficult for stakeholders to understand the study and how it benefits children. A lack of clarity regarding researchers' qualifications can reduce the likelihood of participation and trust among stakeholders.

The second topic, being creative and meaningful, refers to how researchers can meet participants' needs by offering them choices regarding location and approach (Fleming 2011; Moore, McArthur, and Noble-Carr 2018). Researchers are responsible for using appropriate methods to ensure the study is in the CYP's best interests. CYP have emphasized that the research topics must be relevant and meaningful (Mossige and Backe-Hansen (2013). Martins et al. (2018) and Kyritsi (2019) have presented ideas for a child-friendly interface and equipment to make the participation of CYP in research more meaningful for children. Using pictures and conversation cards has also proved useful (Guttormsdóttir and Kristinsdottir 2017; Woodhead & Faulkner, 2000). In addition, several authors propose that researchers could build self-reflection into their work by inviting CYP to provide feedback throughout the process (Fleming 2011; Mossige and Backe-Hansen 2013; Powell et al. 2016). Stakeholders mention that researchers need to clarify their plans to handle data and information, who will benefit from their research, and how to avoid possible harm to CYP involved in the project. Being clear about the benefits for children is not always easy. One reason is that the primary aim of the research is to gain new knowledge. Unless the study is a clinical intervention, it is only sometimes possible to pinpoint the benefits of possible outcomes (Kennan and Dolan 2017).

Additionally, participation in research may not be enjoyable when the topic is sensitive or severe. However, the research design should be creative and exciting for CYP whenever possible. As children and young people say, they would be more likely to participate in a project that at first sight seems fun and exciting than in a project that seems purposeless and boring (Martins, Oliveira, and Tendais 2018), which aligns with the earlier findings of Stafford et al. (2003). To overcome these challenges, the researcher could be more reflective, use a collaborative approach, and focus on relationships built on trust, respect, and transparency (Powell et al. 2018). Kyritsi (2019) and Moore et al. (2018) offer creative solutions to support CYP in making informed decisions. Moore et al. (2018) offer ways to obtain consent using a graphic rather than text format, how best to explain roles, and other tools helpful in overcoming those challenges. Kyritsi (2019) offers a box with cards that

CYP can use to stop or skip a topic at any time during the research process, corresponding to previous findings of Guttormsdóttir and Kristinsdottir (2017). Daley (2015) points out the contradiction in emphasizing the rights of CYP to participate in matters concerning them while simultaneously putting them last in line in obtaining consent. When the line of gatekeepers is long and challenging, particularly in the case of marginalized CYP, the latter might never get to choose whether to participate or express their feelings about participating in research. In this context, it is vital to question whether the safeguarding process protects the system, the gatekeepers, or the CYP.

Building understanding and trust between CYP, gatekeepers and researchers in this context includes addressing how their beliefs, expectations and worries may differ. Building a trustful relationship through reflective discussion in the preparation phase is a process towards mutual understanding on the subject and enhancing the researchers' sensitivity to gatekeepers' concerns and CYP's needs. When striving to reach a mutual understanding with children and gatekeepers, it is essential to consider that child participants and researchers cannot negotiate away the power differences between them. Hence, we must recognize how such power differences form the backdrop of our ethical considerations when including children (Kiili, Moilanen, and Larkins 2023; Moore et al. 2021; Powell et al. 2018, 2020; Turner and Almack 2017). From the researchers' point of view, the process stretching from the initial application to getting access to CYP is often long and challenging. Contacting and getting *buy-in* from the gatekeeper is a challenging task for the researcher, sometimes resulting in the termination of the project (Daley 2015). Previous studies relate that such processes have resulted in the exclusion of children and their voices (Carter 2009; Cojocaru 2013; Gallagher et al. 2012; Roose et al. 2009; Seim and Slettebø 2017; Tunestveit, Njøs, and Seim 2022).

There are two main views on the perception of risk. On the one hand, gatekeepers claim that researchers are not being careful enough; on the other hand, researchers claim that gatekeepers' overprotection hinders CYP's participation (Collings, Grace, and Llewelly 2016; Daley 2015; Kennan and Dolan 2017; Kyritsi 2019; Martins, Oliveira, and Tendais 2018; Powell et al. 2020, 2020; Vaswani 2018). Much of the discussion involves gatekeepers' concerns about what is appropriate when inviting CYP to participate in research. The viewpoint is that CYP are sensitive and should be protected, especially if the subject is considered sensitive. Prior research has shown that gatekeepers often see participation and protection as irreconcilable (Dempsey et al. 2016; Sandberg 2018; Vis, Holtan, and Thomas 2012). CYP's participation needs to be meaningful, powerful, and responsive. To fulfil this, the researcher needs to build in time to increase the possibility for CYP to have a positive experience and feel safe participating (Moore, Noble-Carr, and McArthur 2016). Stakeholders ask that researchers plan for more time and have the competence to build trust and relationships when doing the research. They want to have the opportunity to evaluate the work at hand and get to know the researcher (Martins, Oliveira, and Tendais 2018; Powell et al. 2020; Turner and Almack 2017). This point of view corresponds with other research (Hood et al., 1996; Kennan, Fives, and Canavan 2012; Reeves 2010; Skelton 2008), which has found that researchers should use the time to build trust with those who can assess the researchers' competence. Increased demands for speed and efficiency can be challenging and even a barrier for researchers to reserve time to build relationships and trust with gatekeepers. Researchers are often not given enough time to prepare for these issues, which can lead to the failure of the research and the exclusion of certain groups of potential participants (Cojocaru 2013; Fleming 2011; Garcia-Quiroga and Agoglia 2020; Horwath 2011; Kennan, Fives, and Canavan 2012; Mossige and Backe-Hansen 2013; Perry-Hazan 2016). Input from the individuals in these groups can matter when researchers make evidence-based conclusions about their lives (Drisko and Grady 2015).

Conclusion

To overcome the challenges in accessing CYP and getting their consent in research, researchers should give the concerns of gatekeepers and children more attention. As introduced above, researchers should carefully design their studies to meet the stakeholders' expectations and requirements. When preparing the research plan, they must know how to present their qualifications and experiences working with CYP. In addition, they should include time for building a trusting relationship with stakeholders. By explicitly addressing these concerns in the research processes, researchers can be more successful in involving CYP in research.

For future work, it could be interesting to look at recommendations from Collings et al. (2016) that identify champions, people within an organization with positive experiences working with CYP, who could share success stories about their experiences collaborating with researchers. In addition, champions could run workshops for gatekeepers on CYP's rights to participate in research and how it could benefit them and support gatekeepers in making informed decisions about CYP's participation.

Listening to stakeholders' demands and considering their concerns should increase researchers' likelihood of getting through the gates and asking CYP to participate (Daley 2015; Graham and Powell 2015; Moore, McArthur, and Noble-Carr 2018; Powell et al. 2018, 2020).

Study limitations (1)

This scoping review provides an overview of the challenges researchers need to address in their research plans when they are aiming to include CYP in research. We based the search and the literature identification on a combination of keywords connected to the aim. Although we conducted the literature search using the central social science databases, searching in additional databases with a more comprehensive search of the grey literature might have identified additional publications. Additionally, our procedure may have overlooked one or two relevant studies due to the indexing in research databases. The studies reviewed, however, were diverse concerning context, aim, and scope. This review is limited to identifying specific barriers that authors will mention when planning a study, leaving out more tacit barriers not explicitly communicated in scientific papers.

All the included articles come from the Minority world. None is from the Majority world, which is a significant limitation. Academics have pointed out previous studies' homogeneity and lack of diversity (Tisdall and Punch 2012).

Most of the reviewed research builds on and discusses adults' views on CYP's participation and best practices when attempting to gain access to children and young people and their consent in research due to our sampling criteria. On the other hand, there is a noteworthy increase in research on CYP's participation in decision-making in welfare services (i.e. Cudjoe, Uggerhoj, and Abdullah 2020; Fylkesnes et al. 2021; Husby, Slettebo, and Juul 2018; Kosher and Ben-Arieh 2020; Lauri, Toros, and Lehtme 2021; Mitchell 2022; Nunes 2022; Skauge, Storhaug, and Marthinsen 2021; Toros 2021). These topics are, however, outside the scope of this article. The CYP in the included articles relate what would appeal to them regarding research participation. Future research could address the issue of the hierarchy of gatekeepers and how to ensure that CYP are not the last in line to be invited to participate in research.

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Paper II

Netla – Veftímarit um uppeldi og menntun
Menntavísindasvið Háskóla Íslands

Ritrýnd grein birt 21. nóvember 2015

►► Yfirlit greina

Guðrún Kristinsdóttir og Hervör Alma Árnadóttir

Hliðvörður – hvert er hlutverk þitt?

Þátttaka barna í rannsóknum

► Um höfunda ► Efnisorð

Markmiðið með greininni er að varpa ljósi á reynslu rannsakenda af því að fá formleg leyfi og aðgengi að börnum til að rannsaka hagi þeirra og ræða við þau um málefni sem þau varða. Tilgangurinn er að efla umræðu um málið og vekja athygli á því hver réttur barnanna er í því sambandi. Rannsakendum ber að afla formlegra leyfa stofnana, forsjáraðila og barna við undirbúning rannsókna þar sem börn eru þátttakendur. Í slíkum rannsóknum þurfa rannsakendur oftar en ekki aðstoð við aðgengi að börnum frá stofnunum, fagfólki og forsjáraðilum, svokölluðum hliðvörðum (e. *gatekeepers*). Greinin er byggð á rýnihópaviðtölum og var rætt við starfandi fræðimenn við Háskóla Íslands. Allir höfðu þeir lagt stund á rannsóknir með börnum þar sem þau voru beinir þátttakendur og höfðu talsverða reynslu af samskiptum við hliðverði.

Niðurstöður benda til þess að einfalda þurfi og skýra ferli formlegra leyfa slíkra umsókna hjá nefndum og yfirmönnum stofnana og að ferlið sé flókið, dýrt og tímafrekt. Það sé of persónubundið hvaða upplýsinga sé þörf, það geti verið bundið fræðigrein rannsakanda, og einnig njóti ákveðin svið meira trausts en önnur. Fram kom að stofnanir og fagmenn væru oft treg til þess að opna hlið fyrir rannsakendur þó svo að formleg leyfi lægju fyrir. Margt getur leitt til slíkrar tregðu og nefndar voru ástæður eins og efasemdir um hæfni rannsakenda til þess að ræða við börn og að hlífa eigi þeim við viðkvæmum spurningum. Rannsakendur höfðu á hinn bóginn ekki fundið teljandi fyrirstöðu hjá forsjáraðilum og börnum. Fræðimenn á sviði menntarannsókna höfðu ekki mætt sömu hindrunum hliðvarða og rannsakendur í heilbrigðis- og félagsvísindum. Nýlegar niðurstöður ýmissa athugana sýna óyggjandi hæfni barna til þátttöku í rannsóknum og kallar það á aukna meðvitund um áhrif og hlutverk hliðvarða. Það gæti leitt til fleiri rannsókna um líf og aðstæður barna frá þeirra sjónarhorni.

Gatekeeper - what is your role? Children's participation in research

► About the authors ► Key words

Children's participation in research is often controlled by key professionals and institutions involved with children. They have the role of enabling research and handling access applications. This may involve not recommending or censuring projects that do not meet required ethical standards. Gatekeepers also assess what ethical issues may be at stake and they have to consider protection needs and the rights of children who participate in research. This

includes deciding when and whether it is appropriate or not for children to participate.

Research involving children certainly raises several ethical questions, which need to be addressed by the researcher. The researcher needs to consider questions concerning how best to meet interests of children and participating institutions, including key professionals involved who are required to follow certain standards and have the role of ensuring the quality of research. This paper explores experiences of researchers that have gained formal access to institutions, which enabled them to involve children as active participants in research. It builds on a qualitative research involving focus group interviews with 8 professional researchers affiliated with the University of Iceland. The participants shared a background of having conducted research with children.

The findings indicate that researchers had mixed experiences of dealing with gatekeeping institutions and professionals in those institutions. Barriers identified to access to children participants were unclear evaluations made by gatekeepers regarding their meaning of ´vulnerable´ research topics. Gatekeepers were found to hinder children´s participation on occasions, underpinned by their view of children as primarily vulnerable group rather than as individuals with diverse capabilities and needs which research may need to highlight. Participants commented that personal contacts with professionals often helped them to gain access to children participants. After access had been granted gatekeepers however kept on wanting to be informed about content of interviews, thus posing a risk for the researcher to breach issues of confidentiality and privacy, which however may also be a grey area when involving children in research.

The issue of when it may be ethically sound to break confidentiality needs to be addressed and made more clear in guidelines in research involving children. Researchers that had conducted research in the field of education appeared to face less obstacles than those involved in research in the field of health and social care. There are indications that researchers in the field of educational research will however increasingly be required to get permission for each and every child. This may serve to ensure better ethical standards but may also limit possibilities for researchers to conduct research with children. The findings further indicate that researchers often have to wait long periods for professionals and institutions to respond to their request for permission and assistance to recruit children as participants. Such long waiting periods are costly and time consuming and may discourage researchers from doing research involving children.

Views concerning homogeneity of children and as primarily vulnerable may weaken the validity of research. A view endorsing children as diverse and capable individuals is needed within institutions and from professionals representing them in order to ensure that research outcomes represent diverse views rather than a limited views of children´s lives. We conclude that it may be important to raise awareness amongst professionals and institutions working with children of their key role in facilitating children´s research. Institutions and services need be made aware of current trends in research where children are increasingly approached as capable individuals rather than as vulnerable. Such awareness raising may go a long way in increasing research on children´s life experiences and conditions which brings forward children´s own viewpoints. There is a need to clarify guidelines in research involving children and the role of gatekeeping institutions in the recruitment process. This includes making forms and applications for ethical approval more transparent and based on similar standards across institution involved with children. Researchers should not have to depend on personal relationships with individual professionals in order to gain access to children participants.

Inngangur

Hér á landi hefur nemum í rannsóknartengdu framhaldsnámi í háskóla fjölgað að mun á síðastliðnum áratugum (Hagstofa Íslands, e.d.) og hvetur sú staðreynd til þess að beina sjónum að framkvæmd rannsókna. Á það ekki síst við um rannsóknir meðal þeirra samfélagshópa sem taldir eru viðkvæmir en þar á meðal eru börn. Fræðimönnum og nemendum í framhaldsnámi mæta mörg siðfræði- og aðferðafræðileg álitamál í rannsóknum meðal barna sem huga þarf að. Vísinda- og tækniráð samþykkti í mars 2012 siðareglur fyrir íslenskt vísindasamfélag sem ætlaðar voru til leiðbeiningar um góða starfshætti og til að draga úr hættu á misferli og svikum í vísindum (Alþingi, 2013–2014). Vísindasiðanefndir í mennta- og félagsvísindum eiga sér stutta sögu hér á landi en nokkru lengri í heilbrigðisvísindum (Háskóli Íslands, 2014; Ólöf Ýrr Atladóttir, Ingileif Jónsdóttir og Björn Guðbrandsson, 2013). Það á einnig við um rannsóknarheféir í stofnunum sem sinna börnum og fjölskyldum.

Aukin vitund um réttindi barna og umræða um mannréttindi hefur fjölgað rannsóknum meðal barna og haft marktæk áhrif á hugmyndir manna um nauðsyn og hæfni barna til beinnar þátttöku í rannsóknum (Brady, Shaw, Blades og Davey, 2012; Cater og Øverlien, 2014; Skelton, 2008).

Þegar rannsaka skal menningu og líf barna með þátttöku þeirra sjálfra þarf að huga að nokkrum mikilvægum þáttum. Afla þarf formlegs leyfis stofnana og oft þarf að leita aðstoðar við að afla aðgengis að þátttakendum en það verkefni spannar þá allt rannsóknarferlið og þarf stöðugt að endurskoða (Gilchrist, Rodd, Deery og Marshman, 2013; Johl og Renganathan, 2010; Reeves, 2010). Þeir aðilar sem veita leyfi og aðstoða fræðimenn við aðgengi að vettvangi eru nefndir hliðverðir (e. *gatekeepers*). Hlutverk þeirra er að gæta hagsmuna einstaklinga og þess vettvangs sem ætlunin er að rannsaka (McLaughlin, 2007; Reeves, 2010; Skelton, 2008). Síðast en ekki síst þarf að leita eftir samþykki foreldra og barna.

Rannsóknarniðurstöður benda til þess að þátttaka barna í rannsóknum sé almennt talin flókin. Einkennist það ferli af siðfræðilegum spurningum er varða hæfni, vernd og rétt til þátttöku. Þó svo að nýjar hugmyndir um bernskuna hafi litið dagsins ljós og sýni margvíslega hæfni barna, eimir enn eftir af vantrú á hæfni þeirra til að fjalla um líf sitt og umhverfi. Því er haldið fram að meðal embættismanna og starfsstétta, sem veita þjónustu til hagsbóta fyrir börn og fjölskyldur, sé of mikil áhersla lögð á verndarhugsun í garð barna á kostnað réttar þeirra til þátttöku sem er ein af grunnstoðum laga um samning Sameinuðu þjóðanna um réttindi barnsins nr. 19/2013 (Alderson, 2005; Mayall, 2009; Skelton, 2008).

Hvatann að greininni er meðal annars að finna í eigin reynslu höfunda og nemenda þeirra af því að afla formlegra leyfa og aðgengis vegna þátttöku barna í rannsóknum. Samskipti og samvinna við hliðverði hafa stundum verið ánægjuleg og hvetjandi en á öðrum tímum letjandi eða jafnvel hindrað þau. Viðbrögð embættismanna við leyfisumsóknum vegna rannsókna með þátttöku barna hafa stundum einkennst af fordómum og birtst meðal annars í vantrú á hæfni grunnskólabarna á mið- og unglingastigi til að svara spurningum um efnið sem þau reyndust síðan vel hæf til. Algengt er að nemar í framhaldsnámi á ákveðnum sviðum þurfi að margítreka óskir um leyfi og aðgengi. Þetta tefur þá nám þeirra og getur orðið til þess að þau verði að breyta um áherslur, til dæmis hefur reynst erfitt að fá að tala við börn undir 12 ára aldri.

Markmiðið með greininni er að varpa ljósi á reynslu fræðimanna við Háskóla Íslands af því að sækja um formleg leyfi og fá aðgang að börnum til beinnar þátttöku í rannsóknum. Tilgangurinn er að efla umræðu um málið og vekja til umhugsunar um rétt barnanna. Til að stuðla að markvissu vinnulagi þarf að skoða áskoranir og hindranir sem snerta að-

gengi og leyfi, taka til athugunar hlutverk hliðvarða og ábyrgð fagstétta við að styðja við nýsköpun þekkingar. Ekki leikur vafi á því að þátttaka barna í rannsóknum getur eflt starf í þágu barna og fjölskyldna. Frekari þekking getur auðveldað rannsakendum og stofnunum umrædd ferli og hvatt til athugana á lífi og umhverfi barna.

Þátttaka barna í rannsóknum

Hugmyndir hafa breyst frá því að líta á börn sem hlutlæg viðfangsefni og eign foreldra eða forsjáraðila í það að líta á þau sem sjálfstæða einstaklinga með eigin réttindi (Brady o.fl.; Fleming, 2013; Mayall, 2009). Þessar nýju hugmyndir hafa haft áhrif á lagasetningu en áherslan síðustu áratugi hefur færst frá ríkjandi verndarhugsun til réttar barna til þátttöku og virkni (Guðrún Kristinsdóttir, 2014). Þetta er í samræmi við 12. grein laga um samning Sameinuðu þjóðanna um réttindi barnsins en þar segir að börn eigi rétt á því að láta skoðanir sínar í ljós í öllum málum sem að þeim snúa og að taka eigi tillit til skoðana þeirra í samræmi við aldur og þroska. Á grundvelli þessara hugmynda hafa rannsakendur í bernskufræðum í auknum mæli beint sjónum að börnum og þátttöku (e. *participation*) þeirra bæði sem viðfangs (e. *research subject*) og með þátttöku þeirra í að skipuleggja rannsóknir og taka á annan hátt virkan þátt í rannsóknarferlinu (Fern, 2014; Fleming, 2010).

Þátttaka barna hefur verið gagnrýnd og þeirri spurningu varpað fram hvort ekki beri að hlífa börnum við þátttöku vegna viðkvæmrar stöðu þeirra. Forða eigi börnum frá því áreiti sem þátttaka í rannsóknum hafi í för með sér og rannsakendur eigi frekar að snúa sér til fullorðinna. Allir búi yfir þeirri reynslu að hafa verið börn og séu því færir um að túlka veruleika þeirra. Þessu hefur verið svarað með því að þetta viðhorf samræmist ekki þeirri hugmynd að bernskan sé félagslega mótuð og þar af leiðandi ólík því sem fullorðnir lýsa frá uppvaxtarárum sínum, framlag barna sé háð stað og stund (Corsaro, 2011; Rogoff, 2003; Skelton, 2008).

Hæfni barna

Í stað þess að vera áhorfendur að eigin lífi eru börn nú talin móta félagslegan og menningarlegan veruleika á mikilvægan hátt (Corsaro, 2011; Rogoff, 2003). Þau séu hæf til þess og hafi hlutverki að gegna í þróun samfélaga, meðal annars með virkri þátttöku í rannsóknum um margvísleg málefni (Eriksson, Bruno og Näsman, 2013; Guðrún Kristinsdóttir, 2014; Humphreys og Stanley, 2006; Jóhanna Einarsdóttir og Bryndís Garðarsdóttir, 2012). Bent hefur verið á að börn vilji taka þátt í rannsóknum, meðal annars þegar viðfangsefnið er tilfinningalega erfitt, ef þau álíta að niðurstöður verði nýttar og hafi áhrif á framtíð barna (Mossige og Backe-Hansen, 2013). Sýnt hefur verið fram á að þátttaka geti verið valdeflandi ef faglega er að henni staðið (Fleming, 2010). Ljóst er þó að vanda þarf til upplýsinga og varast að börn vænti of mikils af rannsókn þegar hún er kynnt. Vegna þess hve mikilvægt það er að varpa ljósi á reynslu barna, þarf að víkka þann hóp sem fær tækifæri til að hafa áhrif á aðstæður sínar og annarra með þátttöku í rannsóknum. En það eru ýmis ljón á veginum, fræðimenn hafa til dæmis lýst áhyggjum af því að þótt börn hafi á síðustu árum tekið þátt í rannsóknum í meiri mæli en áður (Morrow, 2008) sé um einsleitan hóp að ræða á afmörkuðum vettvangi (Brady o.fl., 2012).

Ábyrgð rannsakenda

Ábyrgð og völd rannsakenda sem leggja stund á rannsóknir með börnum eru mikil og margar siðferðilegar áskoranir einkenna þá vinnu. Fræðimaðurinn þarf að svara áleitnum spurningum sem geta snert leyfi og aðgengi. Hann þarf að taka tillit til stöðu barna, geta beitt viðeigandi aðferðum og geta sett niðurstöður skilmerkilega fram (Fern, 2014; Guðrún Kristinsdóttir, 2014; Morrow, 2008) á þann hátt að þau skaði ekki eða gangi gegn hagsmunum barna eða annarra (Osborn og Bromfield, 2007). Þá þarf hann að skýra tilgang

rannsókna sinna eins vel og unnt er, svo og rök fyrir mikilvægi hennar og gildi bæði í fræðilegu og hagnýtu tilliti (Mossige og Backe-Hansen, 2013).

Samkvæmt hugmyndum samtímans um stöðu barna er það bæði lagaleg og siðferðileg skylda rannsakenda að virkja börn til þátttöku og taka sjónarmið þeirra alvarlega þegar fjallað er um mál sem varða líf þeirra og aðstæður (*Barnaverndarlög* nr. 80/2002; Graue og Walsh,1998; *Lög um samning Sameinuðu þjóðanna um réttindi barnsins* nr. 19/2013).

Umræðan hefur meðal annars snúist um það að hve miklu leyti athuganir þar sem börn taka þátt séu ólíkar rannsóknum með fullorðnum og hvort og hvernig meta eigi færni barna þegar þau eru spurð um erfið málefni. Börn eiga rétt á þátttöku en líka vernd í samræmi við aldur og þroska. Í því sambandi hefur verið bent á að réttur og vernd eru ekki andstæður heldur eiga þessir þættir að geta unnið saman og stutt hvor annan í því skyni að skapa barnvænlegt rannsóknarumhverfi (Guðrún Kristinsdóttir, 2014; Warren, 2007). Við val á viðfangsefni þarf rannsakandi að vega og meta þær hindranir og hagnýtu aðstæður sem hann kann að mæta. Þetta setur sinn svip á möguleika hans og markar árangur (Sjöström, 2012). Þegar um er að ræða aðstæður sem margir telja viðkvæmar þarf rannsakandi að vera raunsær en þetta á meðal annars við um rannsóknarstarf sem krefst beinnar þátttöku barna. Við undirbúning þarf að tryggja velferð og rétt barns og gera ráð fyrir tíma til þess að vinna að formlegum leyfum og aðgengi eftir aðstæðum. Hafa þarf augun opin fyrir því að aðgengi þarf að vera í sífelldri skoðun meðan á rannsókn stendur (Reeves, 2010; Skelton, 2008).

Persónuvernd og siðanefndir

Á undirbúningsstigi rannsókna þurfa rannsakendur að huga að formlegum atriðum. Algengt er að sundurgreina þetta og ræða um leyfi, aðgengi og samþykki þeirra sem hagsmuna eiga að gæta. Oft er nauðsynlegt að afla leyfis stofnunar til rannsókna. Á sviði félags- eða menntamála getur þetta snúið að félagsmála- eða velferðarráði eða skólanefnd í sveitarfélögum. Þeim ber að standa vörð um hagsmuni fólks er falla undir viðkomandi verksvið og tryggja varðveislu persónuupplýsinga. Einnig er stofnun algengur milliliður (e. *betweeners*) þegar óskað er eftir ábendingum um þátttakendur úr hópi notenda, til dæmis vegna viðtala og vettvangsathugana. Er í þessu sambandi rætt um að afla aðgengis að þátttakendum. Annar hlekkur í þessari keðju er þegar afla þarf persónuupplýsinga úr skrám stofnana. Þá ber ýmist að tilkynna eða sækja um leyfi vegna slíkra áforma til Persónuverndar eftir atvikum sem eru nánar skilgreind í lögum um persónuvernd og meðferð persónuupplýsinga nr. 77/2000. Enn einn liður í aðgengi að þátttakendum er hin vísindasiðfræðilega hlið málsins og sjá vísindasiðanefndir um að tryggja löglega meðferð upplýsinga um einstaklinga og gögn (Háskóli Íslands, 2014).

Fyrir skömmu var stofnuð á vegum Háskóla Íslands vísindasiðanefnd sem standa skal vörð um heilindi fræðimanna og vera rammi um rannsóknir kennara, nemenda og fræðimanna. Í reglum nefndarinnar er tekið fram að mikilvægt sé að börn taki þátt í rannsóknum á viðfangsefnum sem þau varða í samræmi við aldur þeirra og þarfir. Rannsakanda ber að leita umsagnar nefndarinnar ef viðfangsefnið er siðfræðilega viðkvæmt og beinist að einstaklingum í slíkri stöðu. Þegar börn eru þátttakendur er krafist umsagnar vísindasiðanefndar, upplýsts samþykkis foreldra eða forsjáraðila og samþykkis barns svo framarlega sem það er til þess hæft (Háskóli Íslands, 2014). Hafa skal að leiðarljósi að ekki sé hægt að framkvæma rannsóknina með þátttöku fullorðinna með sama árangri. Einnig eru helstu reglur vísindasiðfræðinnar tilgreindar, svo sem að niðurstöður skuli koma þátttakendum til góða, að gæta skuli að lágmarksáhættu í framkvæmd og að allar upplýsingar séu skýrar og skiljanlegar barni. Tryggja þarf að barni sé ljóst að það geti hvenær sem er dregið samþykki sitt til baka og hætt þátttöku án eftirmála (Háskóli Íslands, 2014). Með þessum nýju reglum virðist meginreglan sú að rannsóknir í Háskóla Íslands, þar sem börn

taka beinan þátt, krefjist leyfis vísindasiðanefndar háskólans og er það nýmæli en áður hafði siðanefnd á sviði heilbrigðisrannsókna svipað hlutverk. Um samþykki þátttakenda, foreldra og barna verður rætt síðar í greininni.

Hliðverðir

Hliðvörður á vettvangi rannsókna er sá sem stjórnar aðgengi að rannsóknarvettvangi. Sá getur verið yfirmaður eða framkvæmdastjóri stofnunar, einstaklingur í hópi eða samfélagi sem tekur lokaákvörðun um aðgengi rannsakanda (Jupp, 2006). Hlutverk hliðvarðar er að gæta hagsmuna einstaklinga og þess vettvangs sem ætlunin er að rannsaka (McLaughlin, 2007; Reeves, 2010; Skelton, 2008). Hlutverk hliðvarða hefur lengi verið þekkt í heimi fræðimanna og rannsakendur hafa lýst grýttri leið sinni að þátttakendum þar sem um er að ræða hliðvörslu embættismanna og fagstétta. Þetta á ekki síst við þegar hópur þeirra sem er til rannsóknar er skilgreindur viðkvæmur (Osborn og Bromfield, 2007). Helstu hliðverðir sem snerta rannsóknir með börnum eru stofnanir og fagstéttir sem starfa með börnum, þar með taldir kennarar, foreldrar og aðrir umönnunaraðilar (Danby og Farrell, 2010; Powell og Smith, 2009). Hliðverðir hafa mikið vald enda er það að jafnaði þeirra að opna eða loka hliðum að rannsóknarvettvangi í samræmi við reglur stofnana.

Hlutur stofnana

Stofnanir sem eiga að sinna velferð barna gegna mikilvægu hlutverki hliðvarða. Yfirmenn eða fulltrúar þeirra opna aðgang að fagfólki sem síðan veitir aðgengi og samþykki hjá notendum þjónustustofnunar. Þessir hliðverðir hafa verið kallaðir millilíðir (e. *betweeners*). Þurfa rannsakendur stundum að nota dýrmætan tíma, fé og orku í að vinna og viðhalda trausti þessara aðila. Rannsakendur eru háðir tíma starfsliðsins, góðmennsku og áhuga á því að greiða götu þeirra og rannsóknunum fylgir auðvitað álag á starfsmenn í þessu hlutverki (Heath, Charles, Crow og Wiles, 2007).

Ótvíræðar skyldur hvíla óneitanlega á stofnunum er varða leyfisveitingar. Í lögum er ákvæði um vinnslu persónuupplýsinga og segir meðal annars að hún sé leyfisskyld ef „hún getur falið í sér sérstaka hættu á að farið verði í bága við réttindi og frelsi skráðra aðila“ (*Lög um persónuvernd og meðferð persónuupplýsinga* nr. 77/2000, 33. gr.). Vinnsla skuli þá ekki fara fram án athugunar og samþykkis stofnunar. Ekki er í lögunum rætt sérstaklega um hæfni barna til þátttöku í rannsóknum.

Af þessu leiðir að umsóknarferli krefjast stundum flókins samstarfs við fagstéttir og geta leitt til siðfræðilegra vandkvæða þegar rannsakendur reyna að laga sig að kröfum og reglum stofnana en halda jafnframt fullri tryggð við vísindasiðareglur (Heath o.fl., 2007; Morrow, 2008). Þetta snýst um það að vera trúr tilgangi verkefnisins og því rannsóknarsniði sem fræðimaður telur henta best og virða jafnframt fagmennsku í viðkomandi stofnun en starfsmenn þar þekkja alla jafna best til aðstæðna. Þetta leiðir til þess að margir kjósa að rannsaka vettvang þar sem þeir þekkja til eða hafa verið við störf, meðal annars til að sneiða hjá þeirri miklu vinnu sem fer í það að byggja upp traust stofnana og fagmanna. Persónuleg tengsl rannsakenda við vettvang eru verðmæt en geta verið snúin (Sjöström, 2012).

Fræðimenn hafa tjáð sig um ýmis vandamál vegna hliðvörslu fagstétta sem starfa í þágu barna. Eitt slíkt atriði snýr að því þegar umsókn um leyfi er hafnað. Rök fyrir slíku geta verið að vernda þurfi starfsemina gegn truflunum eða að tíma skorti til að sinna rannsakanda. Þessu kann fræðimaður að eiga erfitt með að mæta ef hann skortir þekkingu á aðstæðum (Sjöström, 2012). Viðhorf hliðvarða til rannsókna geta líka tafið leyfisöflun og hindrað aðgengi að þátttakendum. Þetta getur til dæmis verið háð því hvort og að hvaða marki þeir nýta rannsóknir í starfi og hvort þeir telja rannsóknir gagnlegar (McLaughlin,

2007; Reeves, 2010; Skelton, 2008). Einnig er bent á þá hættu að val þátttakenda skekkist því að sennilegt sé að fagmenn velji síður til þátttöku þá sem eru ósáttir við þjónustu þeirra og frekar hina sem sáttari eru við þjónustuna (Osborn og Bromfield, 2007). Þá eru atriði tengd heilindum, svo sem þegar óskir stjórnenda eða starfsfólks um upplýsingar geta sett rannsakendur í siðferðilegan vanda vegna trúnaðar við þátttakendur (Reeves, 2010). Einnig er nefnt að fræðimenn hafi þurft að hætta við rannsókn vegna þess að fagmenn hafi hindrað þátttöku barna og útilokað þau markvisst frá þátttöku í athugunum (Gilbertson og Barber, 2002). Hefur verið bent á þetta sem brot á *Samningi Sameinuðu þjóðanna um réttindi barna.* Þetta kann að tengjast þeim hugmyndum manna að bernskan sé þróunarskeið og barnið ekki nógu þroskað til að taka þátt í rannsóknum. Þeim sem aðhyllast það sjónarhorn hættir til að vanmeta hæfni barna til að tjá skoðanir og að ekki eigi að taka orð barna alvarlega (James, Jenks og Prout, 2012). Augljóslega þarf að meta hæfni barns og laga sig að henni en ýmislegt bendir til þess að of mikið sé gert úr þessu. Talsverð reynsla hefur orðið til meðal fræðimanna hvað það varðar að beita fjölbreyttum aðferðum við rannsóknir með börnum (Alderson, 2008; Fern; 2014: Mauthner, 1997; Skelton, 2008).

Mikilvægt er að fagmenn sem sinna börnum með hagsmuni þeirra í huga geri sér grein fyrir hæfni þeirra og rétti til þátttöku og gefi sér tíma til að styðja við rannsóknir á þeim vettvangi (Cater og Øverlien, 2014). Þörf er á því að veita fjölbreyttari hópi barna aðkomu að rannsóknum til þess að bæta við þekkingu og þróa heillavænlegar leiðir (Brady o.fl., 2012; Fleming, 2010; Heath o.fl., 2012). Með því má án efa þróa hagnýtar lausnir sem byggjast á reynsluheimi barna en þau setja stundum fram athyglisverðar hugmyndir að slíku (Guðrún Kristinsdóttir, 2014).

Börn og hliðvarsla

Þátttaka barna er háð vilyrðum og skilyrðum þeirra sem annast börn og henni er stjórnað af stigveldi hagsmunaðila. Ekki er hægt að nálgast börn beint til að óska eftir þátttöku þeirra í rannsóknum vegna undirskipaðrar stöðu þeirra í samfélaginu. Fleira kemur þó til, svo sem vilji og skylda til að vernda börn og að taka þarf mið af þroska þeirra og aldri eins og tilgreint er í lögum og reglum.

Samþykki foreldra og barna

Foreldrar og forsjáraðilar gegna mikilvægu hlutverki sem hliðverðir. Ef þeir veita ekki leyfi fyrir rannsókn með börnum sínum og stuðla að framgangi hennar, eru forsendur rannsóknarstarfsins brostnar. Litið er svo á að samþykki foreldra feli í sér að rannsakendur hafi leyfi til að óska eftir samþykki barnsins. Skiptar skoðanir eru um það hvort foreldrar eða forsjáraðilar skuli fara með þann rétt að veita leyfi eða hafna því að barn taki þátt í rannsóknum. Í því sambandi hefur verið spurt hvort verið sé að hlífa barni eða hvort foreldrar eða forsjáraðilar séu að hlífa sjálfum sér og gangi með því á rétt barnsins til að tjá sig (Mossige og Backe-Hansen, 2013). Undirskrift foreldra þýðir ekki að barnið vilji taka þátt heldur opnar hún hlið og veitir rannsakanda leyfi til þess að leita samþykkis barnsins. Þetta er vissulega háð aldri barna. Ekki gilda alls staðar sömu aldursmörk um það hvenær þurfi samþykki forsjáraðila og barna til þátttöku í rannsóknum og slíkar reglur geta jafnvel verið mismunandi innan sama lands (Health Canada, 2012). Hér á landi líkt og í Bretlandi er krafist samþykkis forsjáraðila vegna þátttöku barns undir 18 ára aldri (Háskóli Íslands, 2014; The Research Ethics Guidebook, e.d.). Ástæða væri til að taka aldursmörk vegna samþykkis barna um rannsóknarþátttöku til athugunar hér á landi og mætti þá meðal annars líta til reynslu frá öðrum löndum. Með of háum aldursmörkum eru yngri börn útilokuð frá því að geta tekið þátt í að afla nýrrar þekkingar og það getur vissulega haft áhrif á samfélagið allt. Einnig meta menn hæfni barna á ólíkan hátt en það væri efni í aðra grein sem snertir hæfni, færni, samhengi, áhrif af rannsókn og fleira.

Hvað sem líður aldursmörkum ætti rannsakandi, sem ætlar að leita til hóps barna, til dæmis bekkjardeildar, ávallt að leita samþykkis (e. *consent*) hjá hverju og einu barni en ekki hjá hópnum sem heild vegna hættu á því að barn treysti sér ekki til að synda gegn straumnum ef meirihlutinn samþykkir þátttöku (Mossige og Backe-Hansen, 2013). Á síðustu árum hefur í auknum mæli verið leitað eftir formlegu samþykki frá börnum. Fyrir barn jafnt sem fullorðinn einstakling þýðir það að samþykkja þátttöku að taka tíma frá til að vinna þetta verk, vera tilbúið að spyrja spurninga varðandi rannsóknina og samþykkja eða hafna þátttöku. Það er mikilvæg almenn regla að samþykki þurfi að vera í sífelldri endurskoðun allt ferlið. Þátttakandi á rétt á því að draga þátttöku sína til baka hvenær sem er (Morrow, 2008).

Hér hafa verið reifuð efnisleg atriði er varða formleg leyfi, hliðvörslu og þátttöku barna. Í rannsókninni sem greinin byggist á er leitað svara við eftirfarandi spurningum: Hver er reynsla rannsakenda af því að sækja um leyfi fyrir rannsókn með þátttöku barna? Hver er reynsla rannsakenda af því að fá aðgengi að börnum til að óska eftir þátttöku þeirra í rannsóknum?

Aðferð

Gagna var aflað í janúar 2015 með hálfstöðluðum (e. *semistructured*) rýnihópaviðtölum (e. *focus groups interviewing*) (Sóley S. Bender, 2013; Rubin and Babbie, 2014) með það að markmiði að varpa ljósi á reynslu fræðimanna við Háskóla Íslands af því að fá formleg leyfi og aðgengi að börnum til beinnar þátttöku í rannsóknum.

Þátttakendur

Þátttakendur voru valdir með tilgangsúrtaki (e. *purposeful sampling*) (Silverman, 2013; Sóley S. Bender, 2013), en þeir höfðu allir unnið með þátttöku barna að rannsóknum sem ýmist voru eigindlegar eða megindlegar. Bréf var sent með tölvupósti til starfsmanna innan Háskóla Íslands sem ætla mátti að hefðu reynslu af slíkri rannsóknarvinnu. Bréfinu var síðan fylgt eftir með samtali til að tryggja þátttöku þeirra sem uppfylltu gefnar forsendur og til að leita eftir samþykki þeirra. Nokkrir aðilar sem haft var samband við höfðu ekki ofangreinda reynslu og uppfylltu því ekki þátttökuviðmið. Viðmælendur voru að lokum átta akademískir starfsmenn Háskóla Íslands sem höfðu reynslu af því að vinna rannsóknir á sviði félagsvísinda, heilbrigðisvísinda og menntavísinda.

Rýnihóparnir

Rætt var við viðmælendur í tveimur hópum og fóru viðtölin fram í húsnæði Háskóla Íslands. Hvort þeirra var um 50–60 mínútna langt og heildarfjöldi orða var 18.349. Þau voru hljóðrituð, afrituð orðrétt og marglesin í þeim tilgangi að skoða sameiginlegar og ólíkar áherslur sem er helsti styrkleiki rýnihópaviðtala (Rubin and Babbie, 2014). Byggt er á eigindlegri innihaldsgreiningu (e. *content analysis*) (Rubin and Babbie, 2014). Greind voru fjögur meginefnisatriði, það er breyttar kröfur, orðspor og vettvangur, hæfni og fordómar og að síðustu foreldrar eða forsjáraðilar.

Takmarkanir og siðferðileg álitamál

Rannsóknir þar sem börn eru virkir þátttakendur er fremur nýtt rannsóknarsnið og því er fjöldi rannsakanda með reynslu af því takmarkaður. Rannsakendur lögðu sig fram við að skapa traust andrúmsloft í viðtölunum til þess að þátttakendur gætu tjáð sig óhikað og af hreinskilni. Þetta gekk vel og höfðu þátttakendur frá miklu að segja. Rannsóknin hefur ekki alhæfingargildi og segja niðurstöður aðeins til um reynslu viðkomandi þátttakenda. Áður en viðtölin fóru fram var rætt við þátttakendur um trúnað, nafnleynd og fengið leyfi þeirra til þess að hljóðrita viðtölin. Höfundar hafa mikla reynslu af rannsóknarviðtölum og hafa meðal annars stundað rannsóknir með þátttöku barna.

Niðurstöður

Í þessum kafla verður greint frá helstu niðurstöðum. Þeim er skipt í fjóra hluta eftir þeim efnisatriðum sem voru áberandi í samræðunni og þóttu varpa ljósi á svör við rannsóknarspurningunum.

Breyttar kröfur

Þátttakendur höfðu ólíka reynslu af því að vinna að rannsóknum með þátttöku barna. Sumir höfðu fyrst og fremst rætt við hópa barna en aðrir höfðu aftur á móti reynslu af einstaklingsviðtölum. Þeir sem ekki höfðu reynslu af því að sækja um leyfi til Persónuverndar eða vísindasiðanefnda áttu það sameiginlegt að hafa ekki unnið að rannsókn með þátttöku barna undir 18 ára aldri á allra síðustu árum. Þeir sögðu að landslagið virtist mjög breytt og að meiri kröfur væru nú gerðar til formlegra leyfa. Einnig hefði vitund almennings aukist um rétt sinn og vald til þess að hafna þátttöku:

> ... ég finn mun ... það eru örugglega breytingar í samfélaginu og það er líka kannski, það fer svolítið eftir hópum, en til dæmis, einn sá hópur sem ég rannsakaði mikið um árabil ... það kom varla fyrir hér á árum áður að ég bara gat ekki gert það sem ég þurfti og vildi gera en í dag kemur það meira fyrir ... að foreldrar segja nei.

Viðmælendur sögðust skilja vel að kröfurnar hefðu aukist en höfðu jafnframt áhyggjur af því að þetta myndi hindra rannsóknarstarf með ákveðnum hópum og gera það of flókið til þess að hægt væri að standa í því. Einn hafði reynslu af því að hætta við rannsókn veturinn 2014–2015 vegna þess að honum fannst kerfið of þungt og taldi sig ekki hafa tíma til að afla allra þeirra leyfa sem krafist var:

> Ég hef ekki tíma í þetta ... við vitum alveg að það verður verst að ná ... skriflegu samþykki allra.

Allir nema einn höfðu viðhaft það vinnulag að senda tilkynningu til Persónuverndar eða sækja um formlegt leyfi þangað eða til vísindasiðanefnda og sækja síðan um önnur leyfi. Einn viðmælandi sem hafði langa reynslu af vettvangi hafði unnið þetta öðruvísi og sagði að það hefði skilað sér betri árangri að gera þetta í öfugri röð að reynslan hefði kennt sér að oft væri betra að byrja á því að fá samþykki foreldra og stofnana eins og skóla áður en hið formlega leyfi Vísindasiðanefndar væri fengið:

> ... mér hefur þótt mikilvægt að snúa mér fyrst til foreldranna ... og það er svona ákveðin pressa þá á viðkomandi stofnun ... þegar það eru komin öll samþykki frá barni og foreldri.

Viðmælendur sem sótt höfðu um leyfi vísindasiðanefnda voru sammála um að ferlið tæki langan tíma og setti oft tímaáætlun úr skorðum. Það tæki frá einhverjum vikum upp í jafnvel á annað ár. Einn viðmælandi sagði:

> Í fyrstu fannst mér þetta tímafrekt og erfitt ... svo bara sneri ég við blaðinu á ákveðnum tímapunkti, bæði var ég náttúrlega orðin fljótari að þessu og ég sá hvað þetta var mikill svona gæðastimpill ... og auðveldaði mér að fá samþykki viðkomandi stofnana því ég var að vinna í þessu ferli ... þá er erfiðara fyrir þær að segja nei.

Þannig var viðmælandi með mörg spjót úti og vann samtímis að formlegum leyfum og aðgengi.

Eins og fram hefur komið voru viðmælendur þeirra skoðunar að það krefðist þjálfunar að sækja um formleg leyfi til stofnana eins og Persónuverndar og vísindasiðanefnda. Viðmælandi ræddi um að vísindasiðanefnd á heilbrigðissviði hætti til að vera ekki nógu skýr varðandi það hvað ætti að koma fram í umsókn og að það væri fremur óþægileg staða fyrir umsækjendur. Þetta leiddi til þess að oft þyrfti að senda umsóknir fram og til baka vegna óskýrra leiðbeininga. Því hefði komið fyrir að þótt rannsakandi teldi sig kunna verkferlið hefði hann orðið fyrir því að reglum og viðmiðum virtist skyndilega hafa verið breytt og því hefði umsóknin ekki fengið brautargengi. Það væri því oft og tíðum ekki ljóst hvaða upplýsingar nefndin teldi sig þurfa. Því væri full þörf á því að endurnýja umsóknareyðublöð og gera þau markvissari og skýrari.

Þátttakendur voru sammála um að það væri nauðsynlegt að gera kröfur en að þær þyrftu að vera skýrar og að meðal annars þyrfti að vera ljóst hvaða fylgiskjöl ættu að fylgja umsóknum. Einn viðmælandi lét þess getið að hann hefði margoft sótt um leyfi til vísindasiðanefnda og nú gengi það yfirleitt frekar vel. En það tæki tíma og krefðist mikillar nákvæmni. Reynslan hefði kennt honum mest:

> ... ætli ég hafi ekki skrifað einar tíu, tólf umsóknir til Vísindasiðanefndar út af rannsóknum með börnum, og maður lærir á það hvað þarf að vera til staðar og annað slíkt ... þannig að umsóknir hafa gengið vel í gegn að því tilskildu að það séu öll nauðsynleg fylgiskjöl til staðar ... náttúrlega samþykki við samstarfsstofnun og svo uppáskrift bæði frá börnum og foreldrum ...

Annar viðmælandi kvaðst hafa reynslu af því að sækja um formleg leyfi erlendis og sagði það strangt ferli en að það hefði verið skýrara:

> Maður þarf að útskýra mjög vel alveg hvernig á að nálgast þessi börn ... hvernig ætlarðu að tryggja að ... þau fái þjónustu við hæfi ef að þau eru „risk of harm“ eða þau ... skaðast? Og hvernig ætlarðu að tryggja það að þú talir ekki við börn um hluti sem að valda þeim gríðarlega miklu ... tilfinningalegu uppnámi?

Viðmælandi sagði umsóknareyðublaðið hafa verið skýrt og ef umsóknin væri vel unnin og spurningum svarað skilmerkilega fengist leyfi.

Orðspor og tengsl við vettvang

Orðspor rannsakenda á vettvangi virtist vera þáttur sem skipti miklu máli varðandi aðgengi og leyfi stofnana. Leyfi var tiltölulega auðfengið ef rannsakandi var þekktur innan stofnunarinnar eða nafn hans þekkt vegna fyrri rannsókna og skrifa. Persónuleg tengsl og kunningsskapur virtust skipta miklu máli þegar kom að því að fá aðstoð við að greiða fyrir aðgengi frá fagmönnum og stjórnendum stofnana. Óþekktum aðila og án persónulegra tengsla reyndist mjög erfitt að fá slíkan aðgang. Einn viðmælandi lýsti slíkri reynslu og sagði það hafa verið erfitt og flókið ferli. Hann sagði það hafa verið mjög erfitt að fá aðgang að börnunum til rannsóknar og þótt formlegt leyfi hefði legið fyrir hefði fagfólk verið fullt efasemda og að það hefði tekið langan tíma að ná því trausti sem þurfti til að nálgast þátttakendur.

> Þeir viðmælendur sem voru fyrst og fremst að rannsaka sinn fyrri vettvang og þá jafnvel fyrrverandi vinnustað virtust betur settir varðandi alla aðkomu. Þeir sögðu að þeir byrjuðu oft á því að kanna stöðuna þar sem þeir hefðu persónuleg tengsl til þess að spara sér tíma sem annars færi í það að byggja upp traust og mynda tengsl á nýjum vettvangi.Stundum mætti heyra þegar í upphafi hvort stjórnandi væri jákvæður og samræðan væri þá óformlegri en ella.

Annar sagði:

> ... ég vann þar í 14 ár, og það ríkir mikill trúnaður … þannig að það skiptir máli upp á að fá þetta aðgengi … Í þeim tilvikum þar sem ég hef farið í gegnum aðrar stofnanir þá hef ég stundum þurft að hafa meira fyrir þessu … þá hefur þetta ekki flogið alveg eins ljúft í gegn en alltaf gengið þannig að ég hef aldrei lent í því að fá nei og vera stoppuð af með verkefni sem ég hef verið með.

Viðmælandi bætti við síðar að þó þyrftu rannsakendur alltaf að velta fyrir sér hvort fólk samþykkti þátttöku til þess að gera rannsakanda persónulegan greiða og sagði:

> ... ja, fólk sem til dæmis [hefur] átt bara erfitt með að segja nei við mig vegna þess að það vissi hver ég var.

Annar viðmælandi sagðist hafa þekkt það kerfi mjög vel sem hann var að fara að rannsaka. Hann hefði tvívegis orðið fyrir því að hafa notið velvilja innan kerfisins. Því hefðu formleg leyfi stofnunarinnar gengið greiðlega en þegar kom að því að fá aðstoð fagmanna til að benda á þátttakendur hefði róðurinn þyngst:

> … svo gekk það óskaplega illa og voru viðmælendur heldur færri en að hafði verið stefnt vegna þess að það bara, þeir fundust ekki … hliðin eru svo mörg.

Í öðru tilviki hefði ferlið tekið langan tíma og mikla vinnu en:

> ... það gekk en það var mikil vinna og eftirfylgni og mörg símtöl og svona að fá þessa viðmælendur sem ég á endanum fékk.

Viðmælendur töldu að margt gæti legið að baki því að fagfólk tæki sér langan tíma í það að aðstoða rannsakendur. Fagfólk hefði mikið að gera og léti það því sitja á hakanum að aðstoða rannsakendur, „æ, þetta er bara einhver upp í háskóla“. Einnig hefði þetta með vald að gera, það skipti máli hver bæði um aðstoð og í hvaða stöðu hann væri. Það væri mjög erfitt fyrir nemanda að fá slíka aðstoð. Svo gæti það haft áhrif ef fagmanni fyndist rannsóknin beinast að því að afhjúpa störf hans eða starfssvið, að þátttakandi kynni að segja eitthvað óþægilegt:

> ... þeir þurfa soldið að passa sitt eigið ... „renommé“ ... þetta held ég að komi líka þarna inn.

Þetta gæti síðan leitt til þess að það fólk, sem hliðverðir veldu til þátttöku, væri fremur einsleitur hópur sem hefði átt í árangursríku samstarfi en að þeir veittu öðrum hópum síður aðgang.

Hæfni og fordómar

Allir viðmælendur bjuggu yfir talsverðri reynslu af því að tala við börn, bæði í rannsóknartilgangi og vegna meðferðar. Þeir töldu mikilvægt að búa yfir þeirri reynslu og ákveðinni færni í því að tala við börn og vinna vettvangsrannsóknir með börnum. Þeir höfðu þróað og kynnt sér ýmis tæki til þess að tala við börn og aðstoða þau við að tjá sig, til dæmis með því að styðjast við spil, ljósmyndir, hlutverkaleiki og samræðuspjöld. Þrátt fyrir þessa miklu reynslu höfðu þátttakendur orðið varir við efasemdir og ákveðnar vangaveltur, bæði frá þeim sem veita formleg leyfi og hliðvörðum um kunnáttu þeirra af rannsóknarvettvangi og hæfni við að tala við börn. Einn viðmælenda nefndi sem dæmi að umsækjandi, sem í þessu tilfelli var í framhaldsnámi, hefði haft 12 ára reynslu af því að tala við börn en dregið hefði verið í efa að hann væri fær til þess að eiga rannsóknarviðtöl við börn. Viðmælandi velti fyrir sér hvort það hefði skipt máli að rannsakendi tilheyrði ekki hefðbundinni heilbrigðisstétt og ætlaði að rannsaka þann vettvang. Átti hann þá við hvort það hefði til

dæmis auðveldað leyfisveitingu ef læknir eða hjúkrunarfræðingur hefði einnig staðið að rannsókninni. Efasemdir Vísindasiðanefndar höfðu leitt til þess að mikill tími hefði farið í að senda umsókn fram og til baka, bæta við hana og laga. Loks hefði leyfið fengist með þeim ummælum að ekki mætti ræða við börn yngri en 12 ára. Þetta breytti eðli rannsóknarinnar að sjálfsögðu umtalsvert.

Hversu auðfengnar leyfisveitingar voru og aðgengi reyndist greitt virtist stundum tengjast málaflokknum sem verið var að rannsaka. Viðmælendur töluðu um fordóma, stigma, gagnvart sumum málaflokkum og alls konar staðalhugmyndir. Almennt væru sumir málaflokkar taldir viðkvæmari en aðrir og oft væru lítil rök að baki því sjónarmiði. Viðmælendur nefndu að margt hefði breyst á síðustu tíu árum hvað varðar rannsóknir með börnum. Það hefði verið afar fátítt á liðinni öld að börn væru þátttakendur en meðvitundin um mikilvægi þátttöku þeirra færi vaxandi. Þó mætti enn greina ákveðna hræðslu við það að gefa leyfi fyrir slíkum rannsóknum. Rætt var um ríkjandi hugmyndafræði innan stofnana og mat á því hvað væru viðkvæm málefni og þessu lýstu viðmælendur sem fordómum. Einn viðmælandi, sem hafði reynslu af því að tala við börn sem höfðu flust til landsins, lýsti reynslu sinni þannig:

> Það var rosalega erfitt að fá leyfi frá þeim, meðla annars vegna þess að það var, það virtist vera eða við skynjuðum það að það væri þessi hugmyndafræði og þetta væru svo óskaplega ... viðkvæm börn og maður skynjaði alveg svona staðalmyndir ... við þurftum að rökstyðja alveg rosalega vel að þau yrðu nú ekki í hættu ... en þetta eru bara börn eins og önnur börn.

Í umræðunni um viðkvæma málaflokka var nefnd reynsla rannsakanda af því að sækja um leyfi til þess að ræða við trans-fólk. Þar hefði gengið mjög illa að fá leyfi, umsóknina hefðu þau þurft að senda aftur og aftur. Viðmælandi upplifði fordóma og sagði:

> Við lentum þar í heljarinnar vandræðum því að það var eins og siðanefndin væri svona ofboðslega hrædd um þetta fólk ... þarna fannst mér vera svona einhver staðalímynd af ... transgender fólki. Þetta er náttúrlega bara alls konar fólk.

Foreldrar eða forsjáraðilar

Viðmælendur nefndu foreldra eða forsjáraðila ekki sem fyrirstöðu fyrir aðgengi að börnum að öðru leyti en því að oft gengi illa að innheimta undirrituð leyfi. Innan skólakerfisins tíðkast að senda heim með börnunum kynningarbréf og ósk um leyfi vegna rannsóknar sem þau leggja í skólatöskuna. Bréfin virtust stundum gleymast í töskunni og því ekki komast til skila. Auðvelt væri að fá aðgang að börnum ef foreldrum þætti rannsóknarefnið mikilvægt:

> ... þetta var svo þarft verkefni, það voru allir svo jákvæðir gagnvart þessu ... það leist öllum svo vel á þetta prógram ...

Talsvert virtist vera um það að rannsóknir væru gerðar innan skóla án undirritaðra leyfa. Þá voru foreldrar eða forsjáraðilar beðnir að láta vita ef barnið ætti ekki að taka þátt; þannig væri stuðst við ætlað samþykki (e. *passive consent*). Viðmælendur töldu þetta þó vera víkjandi form, oftar væri nú farið fram á undirritað samþykki og svo væri það líka að aukast að börnin skrifuðu einnig undir en það hefði ekki tíðkast áður. Komið hefði fyrir að foreldrar vildu vera viðstaddir viðtal við barnið. Viðvera foreldra gæti verið styrkur en komið hefði fyrir að foreldri færi að skipta sér af viðtalinu og sumir átt erfitt með að halda sér til hlés. Mikilvægt er að huga að þeim áhrifum sem viðvera foreldra eða forsjáraðila getur haft á viðtalið. Einn viðmælandi sagði:

> ... ein mamman vildi endilega vera með í viðtalinu og stelpan vildi það líka þannig að ég bara ókei en ég vissi það þá að ég þyrfti bara að útskýra það seinna ... hvort og hvernig það myndi hafa haft áhrif á niðurstöður ... Ég fann það alveg að stelpan var vör um sig þegar hún svaraði spurningum af því mamman hafði náttúrlega áhrif.

Hvort rannsakendum fannst stuðningur að viðveru foreldra eða forsjáraðila var háð viðfangsefninu. Einn viðmælandi sagði að sér hefði fundist að sumu leyti gott að hafa foreldra með barninu í einni af sínum rannsóknum vegna þess að þá hefði það legið ljóst fyrir um hvað var rætt og efnið hefði verið þess eðlis að hann taldi það ekki skipta máli.

Rætt var um ábyrgð rannsakenda og valdahlutföll þegar börn eru þátttakendur og mikilvægi þess að rannsakandi sé ígrundandi og endurskoði ávallt þau leyfi sem hann hefur. Viðmælandi sagði í þessu sambandi:

> ... bara mjög ung börn eru mjög ... oft næm fyrir því að maður er bara að horfa, hvað þá með kannski upptökuvél ...

Einn viðmælandi hafði þá reynslu að vera með öll leyfi og vera kominn á vettvang en finna það svo að barninu fannst aðstaða sín óþægileg og ákvað þá að binda enda á viðtalið. Og sagði í því sambandi:

> ... með börn sem ekki eru farin að til dæmis nota tungumálið svona sem megintjáningarleiðina, að maður sé, sko, virkilega vakandi fyrir því, hvort þeim finnst nærvera manns óþægileg eða ógnandi ...

Að lokum var fjallað um mikilvægi þess að undirbúa hliðverði með því að veita þeim greinargóðar upplýsingar á skiljanlegu máli þannig að fagfólk, sem hefði samband við hugsanlega þátttakendur, væri vel undirbúið að kynna rannsóknina. Erlendis væru strangar kröfur gerðar til þess að upplýsingar væru á mannamáli. Rannsakendur útbyggju jafnvel bækling með mynd af sér og lýstu rannsókninni, tilgangi og jafnframt áhættu. Af þessu gætum við lært og það auðveldað samskipti við formlega leyfisveitendur og hliðverði.

Umræða

Innleiðing á meginreglum Vísindasiðanefndar Háskóla Íslands frá árinu 2014 um þátttöku barna í rannsóknum er mikilvægt og löngu tímabært nýmæli sem heyrir til framfara og ætti að skýra framkvæmd. Mikil fjölgun nemenda í rannsóknartengdu framhaldsnámi kallar á þessar endurbætur (Hagstofa Íslands, e.d.). Hvernig til tekst er síðan háð túlkun og framkvæmd. Áhersla á formleg leyfi stofnana líkt og vísindasiðanefnda virðist misjafnlega mikil eftir rannsóknarsviðum. Lengri hefð er fyrir slíkum leyfisveitingum á sviði heilbrigðisvísinda en menntavísinda. Læknar hafa löngum verið í fararbroddi þegar móta skal vísindasiðareglur (Ólöf Ýrr Atladóttir o.fl., 2013; Forsman, 1997). Ýmislegt bendir nú til aukinnar formfestu í framkvæmd rannsókna, meðal annars við öflun leyfa meðal þátttakenda, þar með talið barna. Hvað þau varðar hefur framkvæmd rannsókna verið með ýmsu móti og alþekkt er til dæmis í skólarannsóknum að ætlað samþykki þeirra er stundum látið nægja óháð aldri. Samhliða þessu hefur rannsóknum meðal barna fjölgað á mörgum sviðum og hefur sú þekkingarsköpun leitt fram margar áhugaverðar niðurstöður (Alderson, 2008; Fern, 2014; Jóhanna Einarsdóttir og Bryndís Garðarsdóttir, 2012).

Hvað persónuvernd snertir skulu stofnanir athuga leyfisumsóknir vegna rannsókna sem fram eiga að fara meðal fólks sem þær sinna (*Lög um persónuvernd og meðferð persónuupplýsinga* nr. 77/2000). Ekki er í lögunum rætt sérstaklega um hæfni barna til þátttöku í rannsóknum en krafist er umsagnar Vísindasiðanefndar Háskóla Íslands þegar börn taka

þátt. Reynsla viðmælenda í rýnihópunum var sú að stofnanir og fagmenn mætu hæfni barna til þátttöku á fremur handahófskenndan hátt. Niðurstöður rýnihópaviðtala okkar sýna að þátttakendur telja að í sumum tilvikum hindri hliðverðir rannsóknir með börnum og fæli fólk frá þeim. Viðmælendur nefndu nokkur dæmi um þetta en taka ber fram að úrtak okkar var lítið og ekki verður alhæft á þeim grunni. Á hinn bóginn má nefna að þátttakendur í rýnihópunum bjuggu yfir mikilli reynslu í rannsóknum. Í þessu samhengi veltu þeir fyrir sér hvaða áhrif þetta gæti haft á fræðastarfið. Afleiðingin gæti verið sú að sá hópur sem leyfi fengist fyrir til þátttöku yrði afmarkaðri og einsleitari en ella og er það að mati ýmissa erlendra fræðimanna veikleiki þeirra (Brady o.fl., 2012). Gera þarf þá kröfu til fagmanna sem vinna með börnum að þeir geri sér góða grein fyrir hæfni barna og rétti þeirra til þátttöku í mikilvægum rannsóknum. Þessi réttindi veita börnum tækifæri til að hafa áhrif á líf sitt og umhverfi. Vinna þarf að því að finna jafnvægi milli hæfni og varnarleysis barna þannig að hvorki sé gengið á rétt þeirra til verndar né þátttöku (*Lög um samning Sameinuðu þjóðanna um réttindi barnsins* nr. 19/2013; Mossige og Backe-Hansen, 2013).

Niðurstöður rannsókna benda til þess að möguleikar fræðimanna á aðgengi grundvallist oft á trú stofnana og fagfólks á hæfni barna til þátttöku í rannsóknum fremur en á hugmyndum sem mótast hafa með fræðimönnum um þá hæfni (Skelton, 2008). Í þessu sambandi var einnig rætt um fordóma og hræðslu stofnana og fagfólks við ákveðna hópa samfélagsins. Þessa gjá þarf að brúa. Áríðandi er að þekkingarskortur torveldi ekki eðlilegt aðgengi og komi í veg fyrir að börn taki þátt í rannsóknarstarfi og uppbyggingu þekkingar á þeirra vettvangi (Cater og Øverlien, 2014). Úr þessu kann að einhverju leyti að greiðast þegar fleiri úr fagstéttum sem starfa með börnum hafa lagt stund á rannsóknarnám. Þetta leysir þó líklega ekki öll vandamál við stofnanir þar sem hliðverðir starfa því að ýmsir hagsmunir kunna enn að vera í vegi. Umræðan um persónuleg tengsl og mikilvægi slíkra tengsla til þess að rannsóknarhlið séu opnuð er áhugaverð. Þetta tengist umræðu um gildi trausts í rannsóknum sem þessum og þann tíma sem rannsakendur þurfa að gefa sér til að byggja það upp (Reeves, 2010). Þetta traust er forsenda vandaðra og áreiðanlegra rannsókna.

Vert er að íhuga nánar ummæli viðmælenda þess efnis að stofnanir skorti formfestu, að þær séu „heimilislegar“ en með því er vísað til huglægs mats hliðvarða og óskýrra reglna. Þegar litið er til hliðstæðra erlendra stofnana töldu þátttakendur í rannsókninni að afgreiðsla erlendra vísindasiðanefnda væri formlegri en hér á landi og að þar væru gerðar skýrari kröfur til rannsakenda. Þessi staðhæfing kallar á frekari rannsóknir. Viðmælendur töldu að reglur og kröfur þyrftu að vera gegnsæjar þannig að rannsakendur, sem eru til dæmis nýir á vettvangi, gætu sótt um slík leyfi, sýndu þeir fram á tilskilda hæfni (Háskóli Íslands, 2014).

Viðmælendur ræddu um mikilvægi þess að styðja við aukna umræðu um hlutverk fagmanna sem hliðvarða. Fagmenn væru oft uppteknir af öðrum hlutum og þeir settu aðstoð við rannsóknarfólk ekki í forgang. Þetta er í samræmi við ábendingar Sjöström (2012). Í þessu samhengi er mikilvægt að skoða viðhorf fagmanna til rannsókna. En bent hefur verið á að ef fagmenn nýta ekki niðurstöður rannsókna að jafnaði eða telja þær ekki gagnlegar eða viðeigandi fyrir starfsemi stofnunarinnar, er ólíklegt að þeir forgangsraði aðstoð við rannsóknaraðila (McLaughlin, 2007).

Einnig virðist það sjónarmið ríkjandi að börn séu of viðkvæm til að tjá sig um erfið mál (Heath o.fl., 2007; McLaughlin, 2007). Þetta samræmist reynslu viðmælenda sem urðu að bíða lengi eftir leyfi og aðstoð fagmanna við að útvega leyfi og aðstoða við aðgengi. Þess voru fleiri dæmi að breyta þyrfti rannsóknaráætlun til þess að mæta kröfum stofnunar sem

taldi að börn yngri en 12 ára ættu ekki að taka þátt í rannsóknum og byggði þá afstöðu á ótta við það að þau hlytu skaða af þátttöku sinni.

Lokaorð

Vinna þarf að skilvirkari leiðum til að greiða leiðir rannsakenda að börnum án þess að ganga á rétt þeirra til verndar. Löng bið eftir leyfum og aðgengi má ekki verða til þess að rannsakendur veigri sér við því að fá börn til þátttöku. Rannsóknir sýna að börn geta og vilja taka þátt í rannsóknum að gefnum skilyrðum, til dæmis ef upplýsingar eru skýrar og málfar við hæfi og þegar þau telja að þátttaka þeirra geti gagnast öðrum (Backe-Hansen, 2002, Guðrún Kristinsdóttir, 2014).

Mikilvægt er að rannsakandi hafi þekkingu og reynslu af því að vinna með börnum og tök á að skapa þeim tryggt umhverfi. Niðurstöður okkar benda til þess að skýra þurfi ferli og kröfur sem gerðar eru til rannsókna af þessu tagi. Einnig þarf að taka aldursmörk til athugunar því að telja má þau há hér á landi.

Efla þarf umræðu um þessi mál, bæði meðal rannsakenda og fagmanna og ræða um ábyrgð þeirra og hlutdeild í þekkingarsköpun. Auka þarf þekkingu fagmanna á nauðsyn þess að börn taki virkan þátt í rannsóknum. Það þarf að hvetja til breytinga á viðhorfum, draga úr verndarsýn og stuðla að þátttöku og valdeflingu barna, skapa þeim tækifæri og aðstæður til þess að vera höfundar að eigin lífi. Með auknu rannsóknartengdu háskólanámi standa vonir til þess að rannsóknarlæsi og rannsóknarfærni aukist. Þetta leysir ekki allan vanda en mun án efa skila sér í auknum skilningi á mikilvægi þátttöku og samvinnu við börn um rannsóknir.

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Um höfunda

Guðrún Kristinsdóttir (gkristd@hi.is) er prófessor í menntunarfræðum við Háskóla Íslands og Associate Fellow við University of Warwick í Englandi. Rannsóknir beinast einkum að hag og aðstæðum barna. Bókin *Ofbeldi á heimili: Með augum barna,* sem Guðrún ritstýrði, hlaut Fjöruverðlaunin 2015 og verðlaun Hagþenkis, félags höfunda fræðirita og kennslugagna 2015. Guðrún átti frumkvæði að stofnun Samtaka um rannsóknir í félagsráðgjöf, Ís-Forsa, og einnig að stofnun Rannsóknarstofu í bernsku- og æskulýðsfræðum – BÆR og er þar í stjórn. Guðrún hefur lengi tekið þátt í alþjóðlegu rannsóknarsamstarfi. Hún situr í ritstjórn tímaritsins *Nordic Social Work Research.*

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Efnisorð

börn – aðgengi – hliðverðir – rannsóknir – þátttaka – vald

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Key words
children – access – gatekeeping – research – participation – power

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Guðrún Kristinsdóttir and Hervör Alma Árnadóttir
Gatekeeper – What Is Your Role? Children's Participation in Research
► About the authors ► Keywords

The article aims to shed light on the experiences of researchers in obtaining formal permissions and access to children to study their circumstances and discuss matters that concern them. The purpose is to promote discussion on this topic and raise awareness about children's rights in this context. Researchers are required to obtain formal permissions from institutions, guardians, and the children themselves when preparing studies involving children as participants. In such research, researchers often need assistance from institutions, professionals, and guardians, known as gatekeepers, to gain access to the children. The article is based on focus group interviews with working academics at the University of Iceland. All participants had conducted research involving children as direct participants and had considerable experience communicating with gatekeepers.

Results indicate that the process for obtaining formal permissions for such applications needs to be simplified and clarified by committees and heads of institutions, as the process is complex, expensive, and time-consuming. The information required is too individualised as it can depend on the researcher's discipline, and certain fields are more trusted than others. It was noted that institutions and professionals are often reluctant to open doors for researchers, even when formal permissions are in place. Many factors can contribute to such reluctance, including doubts about the researchers' ability to communicate with children and a belief that children should be shielded from sensitive questions. On the other hand, researchers did not find significant obstacles from guardians and children themselves. Academics in the field of educational research had not encountered the same gatekeeping barriers as those in health and social sciences. Recent findings from various studies demonstrate children's indisputable ability to participate in research, highlighting the need for increased awareness of the influence and role of gatekeepers. This could lead to more research on children's lives and circumstances from their perspectives.

Gatekeeper - what is your role? Children‘s participation in research ► About the authors ► Key words Children‘s participation in research is often controlled by key professionals and institutions involved with children. They have the role of enabling research and handling access applications. This may involve not recommending or censuring projects that do not meet required ethical standards. Gatekeepers also assess what ethical issues may be at stake and they have to consider protection needs and the rights of children who participate in research. This includes deciding when and whether it is appropriate or not for children to participate. Research involving children certainly raises several ethical questions, which need to be addressed by the researcher. The researcher needs to consider questions concerning how best to meet interests of children and participating institutions, including key professionals

involved who are required to follow certain standards and have the role of ensuring the quality of research. This paper explores experiences of researchers that have gained formal access to institutions, which enabled them to involve children as active participants in research. It builds on a qualitative research involving focus group interviews with 8 professional researchers affiliated with the University of Iceland. The participants shared a background of having conducted research with children. The findings indicate that researchers had mixed experiences of dealing with gatekeeping institutions and professionals in those institutions. Barriers identified to access to children participants were unclear evaluations made by gatekeepers regarding their meaning of ´vulnerable´ research topics. Gatekeepers were found to hinder children´s participation on occasions, underpinned by their view of children as primarily vulnerable group rather than as individuals with diverse capabilities and needs which research may need to highlight. Participants commented that personal contacts with professionals often helped them to gain access to children participants. After access had been granted gatekeepers however kept on wanting to be informed about content of interviews, thus posing a risk for the researcher to breach issues of confidentiality and privacy, which however may also be a grey area when involving children in research. The issue of when it may be ethically sound to break confidentiality needs to be addressed and made more clear in guidelines in research involving children. Researchers that had conducted research in the field of education appeared to face less obstacles than those involved in research in the field of health and social care. There are indications that researchers in the field of educational research will however increasingly be required to get permission for each and every child. This may serve to ensure better ethical standards but may also limit possibilities for researchers to conduct research with children. The findings further indicate that researchers often have to wait long periods for professionals and institutions to respond to their request for permission and assistance to recruit children as participants. Such long waiting periods are costly and time consuming and may discourage researchers from doing research involving children. Views concerning homogeneity of children and as primarily vulnerable may weaken the validity of research. A view endorsing children as diverse and capable individuals is needed within institutions and from professionals representing them in order to ensure that research outcomes represent diverse views rather than a limited views of children´s lives. We conclude that it may be important to raise awareness amongst professionals and institutions working with children of their key role in facilitating children´s research. Institutions and services need be made aware of current trends in research where children are increasingly approached as capable individuals rather than as vulnerable. Such awareness raising may go a long way in increasing research on children´s life experiences and conditions which brings forward children´s own viewpoints. There is a need to clarify guidelines in research involving children and the role of gatekeeping institutions in the recruitment process. This includes making forms and applications for ethical approval more transparent and based on similar standards across institution involved with children. Researchers should not have to depend on personal relationships with individual professionals in order to gain access to children participants.

Introduction

In this country (Iceland), the number of students in research-related postgraduate studies at universities has increased significantly in the past decades (Statistics Iceland, et al.), and this fact encourages us to focus on conducting research. This applies particularly to research conducted on social groups that are considered vulnerable, including children. When researching children, academics and graduate students face many ethical and methodological issues that must be considered. In March 2012, the Science and Technology Policy Council approved a code of conduct for the Icelandic scientific community that was intended as a guide to good practice and to mitigate the risk of misconduct and fraud in science (Parliament, 2013–2014). Scientific ethics committees in education and social sciences have a short history in Iceland, but a somewhat longer one in health sciences (University of Iceland, 2014; Ólöf Ýrr Atladóttir, Ingileif Jónsdóttir and Björn Guðbrandsson, 2013). This also applies to research traditions in organisations that care for children and families.

Increased awareness of children's rights and discussions about human rights have increased the number of studies involving children and have had a significant impact on ideas about the necessity and ability of children to participate directly in research (Brady, Shaw, Blades and Davey, 2012; Cater and Øverlien, 2014; Skelton, 2008).

When studying the culture and life of children with their participation, several important aspects must be considered. Formal permission from institutions must be obtained, and support must often be sought to gain access to participants; this task spans the entire research process and must be constantly revised (Gilchrist, Rodd, Deery and Marshman, 2013; Johl and Renganathan, 2010; Reeves, 2010). Those who grant permission and assist researchers with access are referred to as gatekeepers. Their role is to protect the interests of individuals and the field they intend to study (McLaughlin, 2007; Reeves, 2010; Skelton, 2008). Lastly, consent must be obtained from both parents and children.

Research results indicate that children's participation in research is generally considered complex. The process is characterised by ethical questions regarding competence, protection, and the right to participate. Although new ideas about childhood have come to light and reveal children's diverse capabilities, there is still a lingering sense of disbelief in their ability to discuss their lives and their environment. It is claimed that among officials and within professions that provide services for the well-being of children and families, too much emphasis is placed on protective thinking towards children at the expense of their right to participate, which is one of the cornerstones of the law on the United Nations Convention on the Rights of the Child No. 19/2013 (Alderson, 2005; Mayall, 2009; Skelton, 2008).

The impetus for the article comes from, among other things, the authors' and their students' own experiences of obtaining formal permissions and access in relation to children's participation in research. Communication and cooperation with gatekeepers have sometimes been pleasant and encouraging, but at other times discouraging or even obstructive. Officials' reactions to applications for permission for research involving children have sometimes been characterised by prejudice and manifested itself in disbelief in the ability of elementary

school children at the middle and junior levels to answer questions about the subject for which they later proved to be well-qualified. It is common for students in postgraduate studies in certain fields to have to make repeated requests for permission and access. This delays their studies and may cause them to change their focus; for example, it has proven difficult to speak to children under the age of 12.

The article aims to shed light on the experience of academics at the University of Iceland in applying for formal permission and gaining access to children for direct participation in research. The purpose is to promote discussion on the issue and raise awareness of children's rights. To promote a systematic approach, it is necessary to look at the challenges and obstacles related to access and permissions and consider the role of gatekeepers and the responsibility of professionals in supporting the advancement of knowledge. There is no doubt that the participation of children in research can strengthen and benefit their work with children and families. Further knowledge can ease the process for researchers and institutions and encourage investigations into children's lives and environment.

Children's participation in research

Ideas have developed from viewing children as objective subjects and the property of parents or guardians to recognising them as independent individuals with their own rights (Brady et al.; Fleming, 2013; Mayall, 2009). These new ideas have influenced legislation, but the focus in the last few decades has shifted from the prevailing protective thinking to children's rights to participation and engagement (Guðrún Kristinsdóttir, 2014). This is in accordance with Article 12 of the United Nations Convention on the Rights of the Child, which states that children have the right to express their opinions in all matters that concern them and that their opinions should be considered in accordance with their age and development. On the basis of these ideas, researchers in childhood studies have increasingly focused on children and their participation; both as research subjects and through their participation in organising research and actively participating in the research process in other ways (Fern, 2014; Fleming, 2010).

Children's participation has been criticised, and questions have been raised about whether children should participate due to their vulnerable position. The argument is that children should be protected from the difficulties that participation in research entails, and researchers should turn to adults instead. Everyone has had the experience of being a child and is therefore able to interpret their reality. This attitude is not in line with the idea that childhood is socially shaped and therefore different from what adults describe from their formative years; a child's contribution depends on place and time (Corsaro, 2011; Rogoff, 2003; Skelton, 2008).

Children's Competence

Instead of being observers of their own lives, children are now considered to shape social and cultural reality in a significant way (Corsaro, 2011; Rogoff, 2003). They are deemed competent and have a role to play in the development of societies, including through active

participation in research on various issues (Eriksson, Bruno and Näsman, 2013; Guðrún Kristinsdóttir, 2014; Humphreys and Stanley, 2006; Jóhanna Einarsdóttir and Bryndís Garðarsdóttir, 2012). It has been pointed out that children want to participate in research, including when the topic is emotionally challenging if they believe that the results will be utilised and will impact the future of children (Mossige and Backe-Hansen, 2013). It has been demonstrated that participation can be empowering if managed professionally (Fleming, 2010). It is, however, crucial to handle information carefully and avoid children expecting too much from the research when it is introduced to them. Given the importance of illuminating children's experiences, it is necessary to give the opportunity to influence their own circumstances and those of others to a more diverse group through research participation. There are, however, various obstacles to this. Scholars have, for instance, expressed concerns that although children have participated in research more extensively in recent years than previously (Morrow, 2008), the group remains relatively homogeneous and within a limited field (Brady et al., 2012).

The Responsibility of Researchers

Researchers working with children carry a significant level of responsibility and authority, and their work involves many ethical challenges. The researcher must address challenging questions that may impact permissions and access. They must consider the children's circumstances, apply appropriate methods, and present results clearly (Fern, 2014; Guðrún Kristinsdóttir, 2014; Morrow, 2008) in a way that does not harm or conflict with the interests of children or others (Osborn and Bromfield, 2007). They must also clarify the purpose of their research as clearly as possible and present arguments for its importance and value in both theoretical and practical terms (Mossige and Backe-Hansen, 2013).

According to contemporary views on the status of children, it is both a legal and ethical obligation for researchers to involve children in the research process and to take their perspectives seriously when dealing with matters concerning their lives and circumstances (Child Protection Act no. 80/2002; Graue and Walsh, 1998; Law on the United Nations Convention on the Rights of the Child No. 19/2013).

The debate has also focused on the extent to which observations involving children differ from studies with adults and whether and how children's abilities should be assessed when they are asked about complex issues. Children have the right to participate but also to be protected in accordance with their age and maturity. In this context, it has been emphasised that rights and protection are not opposites but should work together and support each other to create a child-friendly research environment (Guðrún Kristinsdóttir, 2014; Warren, 2007). When choosing a subject, the researcher must weigh and evaluate the obstacles and practical conditions they may face. This can influence their opportunities and determine their success (Sjöström, 2012). When dealing with situations considered sensitive by many, the researcher must be realistic; this also applies to research that requires the direct participation of children. During preparation, the well-being and rights of the child must be ensured, and adequate time must be allocated to work on formal permits and accessibility depending on the situation.

There must be an awareness that accessibility needs to be continually reviewed and monitored throughout the research process (Reeves, 2010; Skelton, 2008).

Privacy and Ethics Committees

During the preparation stage of research, researchers need to address formal issues. It is common to break this down into discussions about permissions, access, and consent for those whose interests need protection. It is often necessary to obtain permission from an institution for research. In the social or educational fields, this may involve a social services or welfare council or a school committee in local authorities. These bodies must safeguard the interests of those under their care and ensure their personal information is protected. An organisation is often an intermediary when suggestions are sought about participants from a user group, such as for interviews and field observations. In this context, the focus is on how to gain access to participants. Another aspect is obtaining personal information from institutional records. In such cases, the researcher must either notify or apply for permission from the Data Protection Authority, depending on the circumstances outlined in the Act on Data Protection and Processing of Personal Data No. 77/2000. A further component of access to participants involves the scientific ethical dimension, and scientific ethics committees are responsible for ensuring the legal handling of information about individuals and data (University of Iceland, 2014).

The University of Iceland recently established a scientific ethics committee to uphold academic integrity and provide a framework for research conducted by faculty, students, and researchers. The committee's rules state that it is important for children to participate in research on topics that concern them, in accordance with their age and needs. The researcher must seek the committee's opinion if the subject is ethically sensitive and involves individuals in such situations. When children are participants, a review by the scientific ethics committee, informed consent from parents or guardians, and the child's consent (if they are capable of giving it) is required (University of Iceland, 2014). It should be noted that research involving only adults cannot achieve the same results as research including children. The fundamental rules of scientific ethics are also specified, such as ensuring that results benefit the participants, minimising risks during implementation, and presenting information clearly in a way that children can understand. It must be ensured that the child understands they can withdraw their consent at any time and stop participating without repercussions (University of Iceland, 2014). With these new regulations, the principle seems to be that research at the University of Iceland involving children now requires the approval of the university's scientific ethics committee, a new development, as previously the ethics committee for health research had a similar role. The consent of participants, parents, and children will be discussed later in the article.

Gatekeepers

A gatekeeper in research is someone who controls access to a research setting. This person could be the manager or director of an organisation, an individual within a group, or a member of the community who makes the final decision regarding the researcher's access (Jupp, 2006). The gatekeeper's role is to protect the interests of individuals and the field being investigated (McLaughlin, 2007; Reeves, 2010; Skelton, 2008). The role of gatekeepers has long been established in academia, and researchers have described their challenging path to participants due to gatekeeping by officials and professionals in the field. This is particularly true when the group under investigation is considered vulnerable (Osborn and Bromfield, 2007). The primary gatekeepers involved in research with children are organisations and professionals who work with children, including teachers, parents, and other caregivers (Danby and Farrell, 2010; Powell and Smith, 2009). Gatekeepers wield significant power, as it is generally up to them to open or close the access to the research site according to institutional rules.

Institutional Role

Child welfare agencies play a crucial role as gatekeepers. Managers or their representatives grant access to professionals, who then provide access and consent to the users of the service organisation. These gatekeepers are often referred to as "betweeners." Researchers sometimes have to invest valuable time, money, and energy to gain and maintain the trust of these parties. Researchers depend on the staff's time, goodwill, and interest in facilitating their work, which naturally places pressure on the staff in this role (Heath, Charles, Crow, and Wiles, 2007).

Undeniably, there are clear responsibilities on the authorities providing access. The law includes a provision on the processing of personal information and states, among other things, that it requires permission if "it may involve a significant risk of violating the rights and freedoms of the registered parties" (Act on Personal Protection and Handling of Personal Information No. 77/2000, Article 33). Processing must not take place without examination and approval by the institution. The law does not specifically address children's ability to participate in research.

As a result, the application processes sometimes require complex collaboration with professionals and can lead to ethical dilemmas when researchers attempt to adapt to the requirements and rules of institutions while maintaining full adherence to scientific ethical guidelines (Heath et al., 2007; Morrow, 2008). It involves remaining true to the project's purpose and the research design that the researcher deems most suitable while respecting the professionalism of the institution in question. Nonetheless, the employees there usually know the situation best. This leads many to prefer researching a field they are familiar with or have worked in previously, partly to avoid the extensive effort required to build trust with institutions and professionals. The researchers' relationship with the field is valuable but can be complex (Sjöström, 2012).

Scholars have highlighted various problems arising from gatekeeping by professionals working in the interests of children. One such issue is when an application for access is rejected. Reasons for this may include a need to protect professionals from disruptions or a lack of time to attend to researchers. This can be difficult for a researcher to address if unfamiliar with the situation (Sjöström, 2012). Gatekeeper attitudes toward research can also delay obtaining consent and hinder access to participants. This may depend, for instance, on whether and to what extent they use research in their work and if they find research useful (McLaughlin, 2007; Reeves, 2010; Skelton, 2008). There is also a risk that participant selection may be biased because professionals might be less inclined to involve those dissatisfied with their service and more likely to engage those who are satisfied (Osborn and Bromfield, 2007). Additionally, there are issues related to integrity, such as when requests for information from managers or staff can place researchers in an ethical dilemma due to confidentiality with participants (Reeves, 2010). Furthermore, it has been noted that researchers have had to halt studies because professionals have obstructed children's participation and deliberately excluded them from observations (Gilbertson and Barber, 2002). This has been identified as a violation of the United Nations Convention on the Rights of the Child. This may be related to perceptions that childhood is a developmental stage and that children are not mature enough to participate in research. Those with this perspective underestimate children's ability to express opinions and believe that children's contributions should not be taken seriously (James, Jenks, and Prout, 2012). Clearly, a child's capacity needs to be assessed and adapted to, but there are indications that this issue may be overstated. Significant experience has been gained among scholars in applying diverse methods to research with children (Alderson, 2008; Fern, 2014; Mauthner, 1997; Skelton, 2008).

It is important that professionals who care for children and have their interests at heart recognise their competence and right to participate and take the time to support research in this area (Cater and Øverlien, 2014). There is a need to provide a more diverse group of children with access to research to enhance knowledge and develop promising approaches (Brady et al., 2012; Fleming, 2010; Heath et al., 2012). In doing so, it is possible to develop practical solutions based on children's experiences, as they sometimes offer valuable insights (Guðrún Kristinsdóttir, 2014).

Children and Guardianship

Children's participation is subject to the terms and conditions set by those who care for them and is governed by a hierarchy of stakeholders. Children cannot be approached directly to request their participation in research due to their status as minors in society. However, additional factors need consideration, such as the duty to protect children as well as their maturity and age, as specified in laws and regulations.

Consent of Parents and Children

Parents and guardians play a crucial role as gatekeepers. If they do not give permission for research involving their children or support its progress, the foundation of the research is undermined. Parental consent is understood to mean that researchers have permission to seek the child's consent. Opinions differ on whether parents or guardians should have the right to grant or refuse permission for a child to participate in research. In this regard, the question arises as to whether the child is being protected or if the parents or guardians are protecting themselves, thereby potentially infringing on the child's right to express their views (Mossige and Backe-Hansen, 2013). The parents' signature does not mean that the child wants to participate, but it opens a door and grants the researcher permission to seek the child's consent. This, of course, depends on the child's age. The same age limits do not apply universally regarding the extent to which the consent of guardians and children is required for participation in research, and such rules may even vary within the same country (Health Canada, 2012). Here in Iceland, as in Great Britain, the consent of a guardian is required for the participation of a child under the age of 18 (University of Iceland, 2014; The Research Ethics Guidebook, n.d.). There is a reason to consider age limits for children's consent to research participation in this country, taking into account experiences from other countries. With excessively high age limits, younger children may be excluded from contributing to the acquisition of new knowledge, which could indeed impact society as a whole. People evaluate children's abilities differently, but this would be the subject of another article addressing abilities, skills, context, impact of research, and more.

Regardless of the age limit, a researcher intending to approach a group of children, such as a class, should always seek consent from each individual child rather than the group as a whole, due to the risk that a child might not feel able to dissent if the majority agrees to participate (Mossige and Backe-Hansen, 2013). In recent years, there has been an increasing emphasis on obtaining formal consent from children. For both children and adults, agreeing to participate involves taking time to engage with the process, being willing to ask questions about the study, and deciding whether to agree to or decline participation. It is an important general principle that consent must be continually reviewed throughout the process. Participants have the right to withdraw their participation at any time (Morrow, 2008).

This discussion has addressed material issues concerning formal permissions, guardianship, and children's participation. In the study upon which this article is based, answers are sought to the following questions: What is the experience of researchers in applying for permission to conduct research involving children? What is the researchers' experience in gaining access to children to request their participation in research?

Method

Data were collected in January 2015 through semi-structured focus group interviews (Sóley S. Bender, 2013; Rubin and Babbie, 2014) to illuminate the experiences of academics at the University of Iceland in obtaining formal permission and access to children for direct participation in research.

Participants

The participants were selected using purposeful sampling (Silverman, 2013; Sóley S. Bender, 2013), and all had previously worked on research involving children, whether qualitative or quantitative. A letter was sent by email to employees within the University of Iceland who were likely to have experience with such research. This was followed up with an interview to ensure the participation of those who met the specified criteria and to obtain their consent. Several individuals contacted did not have the aforementioned experience and thus did not meet the participation criteria. Ultimately, the interviewees were eight academic staff members from the University of Iceland with experience in conducting research in the fields of social, health, and education sciences.

The Focus Groups

Interviewees were interviewed in two groups, with the interviews conducted on the premises of the University of Iceland. Each interview lasted approximately 50–60 minutes, and the total number of words was 18,349. They were recorded, transcribed verbatim, and read multiple times to examine common and differing emphases, which is a key strength of focus group interviews (Rubin and Babbie, 2014). The analysis was based on qualitative content analysis (Rubin and Babbie, 2014). Four main topics were analysed: changing requirements, reputation and context, competence and biases, and finally, parents or guardians.

Limitations and Ethical Issues

Research involving children as active participants is a relatively new research format so the number of researchers with experience in this area is limited. The researchers endeavoured to create a trusting atmosphere during the interviews so that participants could express themselves freely and openly. This approach proved successful, and the participants had a lot to contribute. The research findings are not generalisable, and the results reflect only the participants' experiences. Before the interviews, participants were informed about confidentiality and anonymity, and their consent was obtained to record the interviews. The authors have extensive experience conducting research interviews and have previously done research involving children.

Results

In this section, the main results will be presented. They are divided into four sections based on the topics that emerged prominently in the discussions and were considered to provide insights into the research questions.

Changed Requirements

The participants had varied experiences conducting research involving children. Some had primarily conducted group interviews with children, while others had experience with individual interviews. Those who lacked experience in applying for permission from the Personal Data Protection or Scientific Ethics Committees had in common that they had not conducted a study involving children under the age of 18 in recent years. They noted that the landscape seemed to have changed significantly, with more stringent requirements for formal permits now in place. Additionally, public awareness of their right and power to refuse participation had increased:

> ... I feel a difference ... society has probably changed and maybe it also depends a little on the group, for example, one group that I studied extensively for years ... it barely happened years ago that I couldn't just do what I needed and wanted to do, but today it's more common... that parents say no.

The interviewees understood why the formal requirements had increased but were concerned that this would hinder research with certain groups and make the process too complex. One cancelled their research in the winter of 2014–2015 because they found the system too burdensome and felt they did not have time to obtain all the required permits:

> I don't have time for this ... we know very well that it's the most difficult thing to obtain ... everyone's written consent.

All but one had adhered to the practice of sending a notification to the Personal Data Protection Agency or applying for a formal licence there or to the Scientific Ethics Committee before applying for other licences. One interviewee with extensive experience in the field had approached it differently and stated that reversing the order had yielded better results. Their experience had taught them that it is often better to start by obtaining the consent of parents and institutions such as schools before securing official permission from the Scientific Ethics Committee:

> ... I have found it important to approach the parents first ... and then there is a certain pressure on the institution in question ... once consent from the child and parent has been received.

Interviewees who had applied for permission from the Scientific Ethics Committee agreed that the process was time-consuming and often disrupted their schedules. It could take from a few weeks to up to two years. One interviewee said:

> Initially, I thought it was time-consuming and difficult ... then I just turned a corner at a certain point, I became naturally quicker at it and I saw what a significant stamp of quality it is ... it made it easier for me to get the approval of the relevant institutions because I was working within the process ... then it's harder for them to say no.

Thus, the interviewer had many tasks ongoing simultaneously, dealing with formal permits and access.

The interviewees believed that applying for formal licences from organisations such as Personal Data Protection and Scientific Ethics Committees required training. One interviewee mentioned that the scientific ethics committee in the health sector was unclear about what should be stated in an application, which made the process uncomfortable for applicants. This led to applications often being sent back and forth due to unclear instructions. It had happened that, despite the researcher's familiarity with the process, the rules and criteria seemed to have been suddenly changed, resulting in the application not being approved. Consequently, it was often unclear what information the committee required. Therefore, there is a need to update the application forms to make them more targeted and clearer.

The participants agreed that while it was necessary to have requirements, they needed to be clear, and it should be specified which supporting documents should accompany applications. One interviewee noted that they had applied to scientific ethics committees many times and that it usually went quite well now. However, it took time and required great precision. Their experience had taught them:

> ... I think I wrote ten or twelve applications to the Scientific Ethics Committee for research involving children, and you learn from that what needs to be included and other such details ... so my applications have been successful as long as all the necessary supporting documents are attached ... of course, approval from the partner organisation and signatures from both children and parents...

Another interviewee mentioned their experience of applying for formal permits abroad, describing it as a strict process but with clearer requirements:

> You have to explain very clearly how you will approach the children ... how will you ensure that ... they receive appropriate services if they are 'at risk of harm' or if they ... are harmed? And how will you ensure that you do not discuss matters that cause them significant ... emotional distress?

The interviewee noted that the application form was clear, and if the application was well-prepared and the questions answered precisely, a permit would be obtained.

Reputation and Connections to the Institution

The reputation of researchers in the field appeared to be a crucial factor regarding institutional access and permissions. Permission was relatively easy to obtain if the researcher was known within the institution or their name was recognised due to previous research and

publications. Personal relationships and familiarity seemed to be of significant importance when it came to receiving assistance with access from professionals and institutional managers. It proved to be very challenging for an unknown individual without personal connections to gain such access. One interviewee described this experience as a difficult and complex process. They stated that it had been challenging to gain access to children for research, and even though formal permission had been granted, professionals had been full of doubts, and it took a long time to earn the trust needed to approach the participants.

Interviewees who were researching within their previous field or even their former workplace seemed to have better access. They noted that they often began by exploring situations where they had personal connections to save time that would otherwise be spent building trust and forming relationships on a new platform. Sometimes, it could be apparent from the outset whether the manager was positive, resulting in a more informal conversation.

Another interviewee stated:

> ... I worked there for 14 years, and there's a lot of confidentiality ... so it's important to have this access ... In cases where I've gone through other organisations, I've had to put in more effort... then it hasn't gone through as smoothly, but it's always worked out, so I've never received a 'no' or been stopped with a project I've been involved with.

The interviewee later added that researchers always had to consider whether individuals agreed to participate as a personal favour to the researcher, saying:

> ... well, there are people who, for example, [have] just had a hard time saying no to me because they knew who I was.

Another interviewee mentioned that they knew the system they were studying very well. They had enjoyed goodwill within the system on two occasions. In these cases, the organisation's formal permits were obtained smoothly, but obtaining help from professionals to refer them to participants proved more challenging:

> ... then it went badly and there were fewer interviewees than anticipated because they just couldn't be found ... there are so many barriers.

In another case, the process took a long time and required significant effort, but:

> ... it worked, but it required a lot of work, follow-up, and many phone calls to get the participants that I eventually managed to secure.

The interviewees believed there could be many reasons why professionals took a long time to assist researchers. Professionals are very busy and may put researchers on the back burner, thinking, "Oh, it's just someone from the university." It also related to hierarchy; it mattered who was requesting help and what their position was. It would be very difficult for a student to receive assistance. Additionally, if a professional felt that the research was aimed at undermining their work or field, there might be a risk if the research participant disclosed something uncomfortable:

> ... they kind of have to look after their own ... ‘renommé’ (reputation) ... I think this is a factor.

This could lead to the gatekeepers selecting participants who were a more homogeneous group with whom they had previously worked effectively, thereby providing less access to other groups.

Competence and Prejudice

All interviewees had considerable experience in talking to children, both for research purposes and for treatment. They believed it was important to have such experience and specific skills in engaging with and conducting field research with children. They had developed and familiarised themselves with various tools for interacting with children and helping them express themselves, such as using cards, photographs, role-playing games, and dialogue cards. Despite this extensive experience, participants had encountered scepticism and some speculation, both from those granting formal permission and from gatekeepers, regarding their knowledge of the research field and their ability to communicate with children. One interviewee provided an example where the applicant, a graduate student in this case, had 12 years of experience in talking to children, but doubts were expressed about their ability to conduct research interviews with children. The interviewee wondered if it mattered that the researcher did not belong to the traditional health profession they intended to study, suggesting that it might have been easier to obtain a licence if a doctor or nurse had been conducting the research. The doubts of the Scientific Ethics Committee led to significant delays in processing the application, involving numerous revisions and resubmissions. Eventually, permission was granted with the condition that they were not allowed to speak to children under 12 years of age. This, of course, significantly altered the nature of the research.

The ease with which permissions were granted was sometimes related to the subject being researched. The interviewees discussed prejudice and stigma towards certain issues and various stereotypes. In general, some issues were considered more sensitive than others, and often there was little justification for this perspective. The interviewees noted that there had been substantial changes over the past decade regarding research with children. It was extremely rare in the previous century for children to participate, but awareness of the importance of their participation is growing. However, a certain degree of fear could still be detected when granting permission for such research. There was a discussion about the dominant ideology within institutions and an assessment of what constituted sensitive issues, which the interviewees described as prejudice. One interviewee, who had experience talking to children who had immigrated to the country, described their experience as follows:

> It was extremely difficult to obtain permission from them, partly because it seemed, or we perceived, that there was this ideology and these were such incredibly ... sensitive children, and you could sense such stereotypes ... we had to justify beyond

> any doubt that they would not be in danger ... but these are just children like any other children.

In the discussion about sensitive issues, a researcher's experience of applying for permission to talk to trans people was mentioned. It was very challenging to obtain a permit, and they had to submit the application repeatedly. They felt this was due to prejudice and said:

> We encountered a hell of a lot of problems there because it was as if the ethics committee was incredibly protective of these people... I felt there was some sort of stereotype about... transgender people. Who are, of course, all sorts of people.

Parents or Guardians

The interviewees did not mention parents or guardians as a significant barrier to accessing children, other than that it is often difficult to collect signed consent forms. Within the school system, it is the norm to send the children home with an introductory letter and a request for research participation, which they put in their school bags. The letters sometimes get forgotten in their bags and fail to reach the parents. Access to children was easier if parents considered the research topic to be important:

> ... it was such a necessary project; everyone was so positive about it ... everyone liked this programme so much ...

There appeared to be considerable research conducted within schools without formal signed consent. Parents or guardians were then asked to inform the researchers if the child should not participate, relying on passive consent. However, the interviewees regarded this as a secondary method; signed consent was more common, and it was also increasingly common for the children themselves to sign the consent form, which was not previously the case. There had been instances where parents wished to be present during the interview with the child. While the presence of parents could be beneficial, there were also cases where parents interfered with the interview, and some struggled to refrain from speaking. It is important to consider the impact that the presence of parents or guardians can have on the interview. One interviewee said:

> ... one of the mothers really wanted to be included in the interview and the girl wanted it too, so I just said ok, but I knew that I would have to explain it later ... if and how it had affected the results ... It was obvious to me that the girl was cautious when she answered questions because she was naturally aware of her mother's presence.

Whether the researchers felt supported by the presence of parents or guardians depended on the subject matter. One interviewee noted that, in some ways, it was beneficial to have a parent present in one of their studies because it clarified what had been discussed, and the nature of the topic was such that they did not consider it crucial.

The interviewees discussed the responsibility of researchers, the power dynamics when children are involved, and the importance of the researcher being reflective and continuously reviewing the permissions that have been given. One interviewee said in this regard:

> ... even very young children are very … often sensitive to the fact that you are observing them, even with a video camera ...

One interviewee had the experience of having all the necessary permits but found that the child felt uncomfortable upon arrival and decided to end the interview. They said:

> ... with children who, for example, have not yet started to use language as their primary means of expression, you need to be highly alert to whether they find your presence uncomfortable or threatening ...

Finally, the importance of preparing gatekeepers was discussed. They should be provided with clear information in accessible language so that professionals who contact potential participants are well-prepared to present the study. Abroad, strict requirements are in place for information to be in plain, non-technical language. The researchers even developed a brochure with a picture of themselves and described the study, its purpose, and its risks. We could learn from this approach, as it would facilitate better communication with officials and gatekeepers.

Discussion

The implementation of the principles set out by the Scientific Ethics Committee of the University of Iceland in 2014 regarding the participation of children in research is a significant and long-overdue development. It calls for progress and should enhance clarity in its execution. The significant increase in students pursuing research-based postgraduate studies underscores the need for these reforms (Statistics Iceland, n.d.). The outcome will depend on interpretation and application. Emphasis on formal permissions from institutions, such as scientific ethics committees, appears to vary considerably across research fields. The health sciences have a longer tradition of such licensure compared to education. Medical professionals have long been at the forefront of developing scientific ethics (Ólöf Ýrr Atladóttir et al., 2013; Forsman, 1997). Several indicators now suggest a trend towards increased formality in research practices, including when obtaining permission from participants, such as children. Research involving children has been conducted in various ways, and it is common knowledge, for instance, in school research, that implied consent is sometimes deemed sufficient, regardless of age. Concurrently, the number of studies involving children has risen across many fields, leading to many interesting findings (Alderson, 2008; Fern, 2014; Jóhanna Einarsdóttir and Bryndís Garðarsdóttir, 2012).

Regarding personal protection, institutions must review research licence applications involving individuals under their care (Act on Personal Protection and Handling of Personal Information No. 77/2000). Although the law does not specifically address children's capacity to participate in research, approval from the Scientific Ethics Committee of the University of

Iceland is required when children are involved. Focus group interviewees reported that institutions and professionals assess children's capacity to participate in a rather ad hoc manner. Our focus group interviews indicate that participants believe that, in some cases, gatekeepers hinder and discourage research with children. Several examples were mentioned, but it should be noted that our sample was small and therefore not representative. On the other hand, it is worth noting that the participants in the focus groups had considerable experience in research. In this context, they questioned what impact this might have on academic work. The consequence could be that the group allowed to participate may be more narrowly defined and homogeneous than otherwise, which, according to various international scholars, is a weakness (Brady et al., 2012). Professionals working with children should be required to have a thorough understanding of children's capacities and their right to participate in significant research. These rights give children the opportunity to influence their lives and environments. Efforts must be made to balance children's competence and vulnerability to ensure that their rights to protection and participation are not compromised (Law on the United Nations Convention on the Rights of the Child No. 19/2013; Mossige and Backe-Hansen, 2013).

Research results indicate that researchers' opportunities for access often rely on the beliefs of institutions and professionals regarding children's capacity to participate in research, rather than on researchers' own understanding of that capacity (Skelton, 2008). This is related to discussions about prejudice and fear among institutions and professionals towards certain societal groups. This gap needs to be addressed. A lack of knowledge should not impede reasonable access or prevent children from participating in research and contributing to the advancement of knowledge in this field (Cater and Øverlien, 2014). This issue may be partly resolved when more professionals working with children engage in research training. However, this does not fully resolve all problems with institutions where gatekeepers operate, as various interests may still obstruct progress. The discussion on personal relationships and the importance of such relationships in facilitating research access is intriguing. This relates to the debate about the value of trust in research and the time required for researchers to build it (Reeves, 2010). Such trust is essential for conducting thorough and reliable research.

Further attention should be given to the interviewees' comments about the lack of formality in institutions and the perception that they are "informal," which refers to gatekeepers' subjective assessments and unclear rules. When compared to similar foreign institutions, participants in the study believed that the processes of foreign scientific ethics committees were more formal than in Iceland and that there were clearer requirements for researchers. This observation warrants further investigation. Interviewees felt that rules and requirements needed to be transparent so that researchers, particularly those new to the field, could apply for such permits if they demonstrated the necessary qualifications (University of Iceland, 2014).

Interviewees emphasised the importance of fostering more discussion on the role of professionals as gatekeepers. Professionals are often preoccupied with other matters and do not prioritise supporting research staff. This aligns with Sjöström's (2012) observations. In this context, it is crucial to examine professionals' attitudes towards research. It has been

noted that if professionals do not utilise research findings or do not view them as useful or relevant to their organisation's activities, they are unlikely to prioritise supporting researchers (McLaughlin, 2007).

A prevailing view seems to be that children are too sensitive to discuss difficult issues (Heath et al., 2007; McLaughlin, 2007). This aligns with interviewees' experiences of delays in obtaining permits and support from professionals in providing permits and facilitating access. There were also more instances of needing to alter research plans to comply with the requirements of organisations that believed children under the age of 12 should not participate in research due to concerns about potential harm from their involvement.

Final Words

There needs to be progress in developing more efficient methods to facilitate researchers' access to children without infringing upon their right to protection. Prolonged waits for permits and access should not deter researchers from involving children. Research indicates that children are willing and able to participate in studies under certain conditions, such as when the information is clear, the language is appropriate, and they believe that their participation will benefit others (Backe-Hansen, 2002; Guðrún Kristinsdóttir, 2014).

It is crucial for researchers to possess knowledge and experience in working with children and to create a safe environment for them. Our findings suggest that the processes and requirements for conducting this type of research need to be clarified. Additionally, age limits should be reconsidered as they are perceived as high in this country.

Discussion on these matters should be encouraged, both among researchers and professionals, as well as regarding their responsibilities and involvement in knowledge creation. Professionals need to be more aware of the necessity for children to actively participate in research. Changes in attitude should be promoted to reduce protectionist views and to enhance the participation and empowerment of children, providing opportunities and conditions for them to shape their own lives. With an increase in research-oriented university studies, there is hope that research literacy and skills will improve. Although this does not resolve all issues, it will undoubtedly contribute to a greater understanding of the importance of involving and collaborating with children in research.

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Invisible children and young people in Child Protection Services

Ósýnileg börn í barnaverndarþjónustu

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ABSTRACT

This article examines the perspective of social workers in Child Protection Services (CPS) on children's and young people's (CYP) right to participate in research while ensuring their right to protection. This study aims to understand how CPS social workers manage the balance between participation and protection and perceive their roles as gatekeepers. Researchers describe accessing CYP in research settings as often challenging, and gatekeepers are criticised for not fully understanding CYP's right to participate in research. Excluding CYP can lead to inaccurate second-hand accounts of their experiences. Data were collected from 17 Icelandic social workers through five semi-structured focus group interviews and analysed thematically. The findings indicate that many social workers find it challenging to prioritise and support CYP participation while ensuring their protection. Due to their vulnerability, some believe that CYP may not handle the stress of participation. Others argue that CPS managers should be responsible for facilitating research access. A few social workers suggested alternative methods like reviewing case files or speaking with adults who had received support from CPS when they were younger. This study concludes that to enhance CYP participation in research, researchers must articulate their aims and relevance while demonstrating their experience working with CYP.

ÁGRIP

Greinin fjallar um sjónarhorn félagsráðgjafa í barnaverndarþjónustu á rétt barna til að taka þátt í rannsóknum á sama tíma og réttur barna til verndar er tryggður. Rannsóknin miðar að því að skilja hvernig félagsráðgjafar finna jafnvægi milli þátttöku og verndar og hlutverk sitt sem hliðverðir. Rannsakendur hafa lýst því sem flóknu ferli að fá aðgengi að börnum til þátttöku í rannsóknum og gagnrýna hliðverði fyrir að virða ekki rétt barna til þátttöku. Gögnum var safnað með fimm hálfstöðluðum rýnihópaviðtölum við 17 félagsráðgjafa. Niðurstöðurnar benda til að mörgum félagsráðgjöfum finnst erfitt að finna jafnvægi milli verndar og þátttöku. Vegna varnarleysis þessa hóps töldu sumir félagsráðgjafanna að börn ráði ekki við þá streitu sem fylgir þátttöku í rannsóknum. Sumir töldu að hliðvarsla ætti ekki að vera í verkahring þeirra heldur stjórnenda sem vinna ekki með börnum daglega. Rætt var um aðrar aðferðir eins og að fá aðgengi að málaskrám sem fagfólk hefur skrifað um börn og nota þau gögn í stað þess að tala við börn. Til þess að auka þátttöku barna í rannsóknum, verða rannsakendur að setja fram skýr markmið og tilgreina mikilvægi rannsóknarinnar auk þess að sýna fram á reynslu og hæfni í því að vinna með börnum.

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This article has been corrected with minor changes. These changes do not impact the academic content of the article.

Introduction

This article examines how CPS social workers in Iceland balance children and young people's (CYP) right to participate in research with their obligation to ensure their right to protection, as required by law.

Contemporary childhood sociology views CYP as skilful actors capable of participating in decisions about their lives (Bluebond-Langner & Korbin, 2007; James et al., 2012; Qvortrup, 1994). Accordingly, their legal rights to participate in matters relevant to their lives have increased significantly, as reflected in the United Nations Convention on the Rights of the Child (UNCRC, 1989). These rights aim to make the diverse group of CYP more visible in society (Brady et al., 2012; Nybell, 2013; Rogoff, 2003; Wells, 2021).

Arguments for CYPs' participation in research are, in addition, linked to the benefits for CYP who participate in research. Society's perspective has shifted from merely protecting CYP and shielding them from potential risks in research participation to also recognising their right to benefit from participation in research (Modi, 2020). Research findings suggest that creating space for children in discussions and decisions about issues concerning them leads to services that better meet their needs. Participation is also empowering for children and can be advocated for as a right and valuable principle (Olsen, 2024). Moreover, for children and young people, sharing their unique perspectives and experiences within the CPS can foster a sense of belonging, positively impact their well-being, and strengthen their sense of identity (Fleming, 2011; Horwath et al., 2012; MacDonald, 2017; Moore et al., 2018; Moore et al., 2021; Seim & Slettebø, 2017; Stafford et al., 2021; Vis et al., 2012; Woolfson et al., 2010).

Studies indicate that managers and practitioners, as gatekeepers in CPS, have excluded CYP from research because they see them as too vulnerable and needing protection from participation (Beresford & Branfield, 2012). With that consequence, their rights are disrespected, as well as opportunities to influence their life and environment (Garcia-Quiroga & Agoglia, 2020; Kosher & Ben-Arieh, 2020; Toros, 2021; Tunestveit et al., 2022; Van Bijleveld et al., 2015). Research with CYP could raise questions about the responsibility of practitioners who deal with tensions between respecting CYP's right to participate in research and protecting them from potential harm (Arnadottir et al., 2023; Dempsey et al., 2016; Sandberg, 2018; Vis et al., 2012). Researchers have occasionally described the process of approaching CYP to seek their consent for participation in research as an insurmountable challenge (Daley, 2015; Vaswani, 2018). To overcome this challenge, researchers have found it essential to raise awareness among gatekeepers and inform them of CYP's right to participate in matters concerning them, including in research (Heimer et al., 2018; Kristinsdottir & Arnadottir, 2015; Tunestveit et al., 2022; Van Bijleveld et al., 2015).

Children and young people's participation in research

The UNCRC (1989) defines children as individuals between 0 and 18 years of age. Article 12 of the UNCRC stipulates children's rights to be heard and express their views of all matters affecting them, according to age and maturity (UNCRC, 1989). Participation is understood as CYP being heard and taken seriously (Hart, 1992; Pölkki et al., 2012; Shier, 2001). Meaningful participation is defined as a process where CYP engage in conversations about issues that concern them, guided by mutual respect towards a common goal (Pölkki et al., 2012; Skauge et al., 2021).

With an increased emphasis in social work on evidence-informed approaches to practice and evidence-based practice, which is defined as integrating research evidence into the decision-making process, gathering data from all demographic groups, including CYP, is crucial. Such data collection is essential for policymaking and the development of effective services (Drisko & Grady, 2015; Kennan et al., 2012; Kiili et al., 2023; Seim & Slettebø, 2017; Stabler et al., 2020; Wodarski et al., 2015).

Research with CYP must always be conducted professionally, ensuring that while participation is crucial, CYP also have the right to be protected from harm (UNCRC, 1989; Woodgate et al., 2017). In

this context, researchers must seek approval from an ethical committee when undertaking research involving CYP and obtaining their consent. Following this, they must secure endorsement and assistance from various formal and informal gatekeepers mediating access to CYP (Danby & Farrell, 2010; Powell & Smith, 2009). Gatekeepers have formal or informal authority to grant permission/access to approach other individuals (Graham et al., 2013). Formal gatekeepers could be managers in welfare organisations, while informal gatekeepers could be practitioners in CPS. The process of obtaining permissions and access can be complex, unclear, and time-consuming, often discouraging researchers from conducting research (Kennan et al., 2012; Kristinsdottir & Arnadottir, 2015). Gatekeepers who are responsible for CYP well-being call for established, trusted relationships with researchers and that researchers cooperate more with the gatekeepers during the preparation phase in order to increase gatekeepers' understanding that the subject will not harm the CYP (Moore et al., 2021; Powell et al., 2020; Powell et al., 2018; Turner & Almack, 2017). Vis et al. (2012) criticise researchers for being vague and imprecise in their access requests, particularly in ensuring safety. Findings from other researchers indicate that gatekeepers find it challenging to evaluate the research if the objectives are unclear and may/may not ensure the physical and emotional safety of CYP (Martins et al., 2018; Moore et al., 2021; Powell et al., 2018; Vaswani, 2018). Participation and protection are both essential subjects in CPS. When practitioners play the role of gatekeepers, they must find a balance between participation and protection, recognising these concepts as mutually supportive. Neither principle can exist without the other (Kristinsdottir & Arnadottir, 2015; Skelton, 2008; Vis et al., 2012). From the viewpoint of protection, safeguarding CYP is vital because of their often marginalised positions within society and their lack of power. From a participation viewpoint, one must recognise CYP as agents in their own lives with the skills and abilities to influence society through participation (Kennan & Dolan, 2017; Sandberg, 2018). Scholars have indicated a tendency within welfare systems to overprotect CYP in vulnerable situations and limit their agency (Kosher & Ben-Arieh, 2020; Tunestveit et al., 2022; Vis et al., 2012). As a result, CYP neither enjoy their legal rights nor have the opportunity to influence their situations or the development of the intended services (Cossar et al., 2016; Daley, 2015; Heimer et al., 2018; Kennan & Dolan, 2017; Tunestveit et al., 2022; Woolfson et al., 2010).

Researchers have noted that one reason for the lack of CYP's participation in research is the difficulty in gaining access to CYP (Kristinsdottir & Arnadottir, 2015). Limited research has explored the perspectives and understanding of social workers in CPS regarding gatekeeping and the challenges of supporting researchers in accessing CYP (Arnadottir et al., 2023). Therefore, it is crucial to examine the perspectives of social workers in Icelandic child protection services, who act as gatekeepers in this context. This article addresses the following research questions:

1. How do social workers balance participation and protection when supporting CYP's participation in research?
2. How do social workers understand their roles as gatekeepers?

Methods

The theoretical perspective underpinning the study is drawn from the interdisciplinary field of Childhood Studies. This field views CYP as capable of participating and holding the right to do so and as the best informants for research about their own lives and circumstances. The research examines how social workers in CPS in Iceland approach CYP's right to participate in research. Specifically, the findings reported here focus on social workers' perspectives on how they support CYP's participation in research. The data were collected from 17 social workers in Iceland through five semi-structured focus group interviews from May 2016 to March 2023, a prolonged period because of the COVID-19 pandemic from 2020–2022.

Participants

The sample criterion was that participants should be front-line social workers in CPS. The handling of inquiries to access participants for the research varies in Iceland, depending on the organisation of municipalities. In larger municipalities, we contacted managers in charge of research and development, who referred the matter to a CPS administrator. In smaller municipalities, we contacted the manager of CPS directly to obtain permission to conduct the study. In all cases, the manager in charge selected the participants. To obtain different views (heterogeneity), we asked the managers to consider various factors, such as gender (if possible), age, and years of experience as social workers. After receiving the names of twenty-one prospective practitioners, we emailed them detailed information about the project and followed up with a phone call. All the practitioners we contacted agreed to participate. Four participants withdrew from the project at the last minute for personal reasons. The final sample consisted of five focus groups: four with three participants and one with five participants, a total of 17 participants (Table 1).

The seventeen participants were all women between the ages of 32 and 63. Their social work experience ranged from two to 31 years. Twelve of the seventeen participants had completed a master's degree in social work within the last 12 years.

Data collection

The main focus of this qualitative research is to explore how research involving CYP in Iceland upheld CYP's participation rights. We gathered data through semi-structured focus group interviews conducted at the participants' workplaces during working hours, at their request. The first author moderated all focus groups. At the start of each session, participants were invited to introduce themselves by name and share the length of their experience as social workers. She encouraged participants to ask questions about the project and her professional background to foster an open and trusting atmosphere.

The moderator presented the content of the interview, the definition of a focus group interview, and the research objectives. The participants read and signed the consent form before the interview started.

The interviews lasted between 55 and 90 minutes, and the total number of words was 28,814. The first author recorded the interviews using a digital tool and transcribed them verbatim.

Ethical issues

We reported the study to the Data Protection Institute in Iceland. The participants came from four municipalities in Iceland, varying in size, services, and structures. Permission was needed from the heads of the organisations to search for participants, in most cases from their managers, depending on the rules of each institution.

Participants were informed about the research through an email letter of introduction before the interview. We then asked them to sign a confidentiality form, ensuring their anonymity and allowing the audio recording of the interviews. This transparent approach ensures that the participants are fully aware of the process and their role in it.

Table 1. Overview of participants in focus groups.

Focus group no.	Year of the interview	Participants no.	Practicing as a social worker
FG_1	2016	3 participants	from 5 – 10 years
FG_2	2019	3 participants	from 3 – 31 years
FG_3	2019	3 participants	from 2 – 24 years
FG_4	2019	3 participants	from 5 – 16 years
FG_5	2023	5 participants	from 2 – 22 years

Analysis

The research team read the transcriptions of the interviews several times to understand the meaning and examine common and divergent emphases, which is a significant strength of focus group interviews. The research questions were experiential and exploratory, thus well suited for thematic analysis (Braun & Clarke, 2013). The analysis followed the principles of the six-phase process of reflexive thematic analysis (Braun & Clarke, 2013; Clarke & Braun, 2017). We transcribed the data and thoroughly reviewed the text. Next, we conducted open coding followed by selective coding to identify patterns in the text. We then analysed the coded data to identify initial themes, reflecting on our methods and developing these themes further.

Finally, we connected these themes to our research questions, revisited emerging concepts, deepened our understanding of the themes, and interpreted the key messages within the data. In the analysis, we examined two topics. The first was *finding a balance between participation and protection*, which we divided into two themes: (1) How to protect the vulnerable CYP and (2) using social workers' working notes and reports instead of involving CYP in research. The second was *the participants' understanding of the role of gatekeepers*, which we also divided into two themes, namely, (1) whose role it is to open the gate and (2) when to open the gate. We will explain these topics in the following section.

Findings

This study focused on how CPS social workers in Iceland approach CYP's right to participate in research while ensuring their right to protection. The participants expressed different perspectives depending on the position of the CYP involved and the participants' ideas about their roles and responsibilities as gatekeepers.

Finding a balance between participation and protection

Lively discussions around CYP's right to participate in research occurred in all focus groups. The interviewees believed that CYP's participation in research was meaningful for individuals and for the Child Protection Services. In the discussions, however, we identified a certain ambivalence. On the one hand, the participants considered CYP's participation in research vital for developing services and policy. On the other hand, in most cases, they considered the CYP unable to participate in discussions about complicated situations in research settings and too sensitive to be involved in research.

The participants agreed that there is a need for more research in child protection, even if they did not think much about research in their daily work. Participants in all focus groups attended courses on CYP's participation during their master's degrees. At that time, they had investigated research and developed awareness about CYP's rights, according to the UNCRC. They expressed interest in childcare issues and said that too few researchers worked on matters connected to children's environments. One participant mentioned that they were always working for the benefit of children and said: 'it would be incredibly valuable to get reliable research about what can be done better in child protection services' [FG.2].

To protect vulnerable CYP

There appears to be a paradox when participants both report that research would lead to a better understanding of CYP's reality and their point of view whilst admitting that they are not reading or using research in their daily work. In four of the five focus groups, the participants expressed doubts that the researchers could always guarantee the safety of the children. One participant said, 'I would be a little bit afraid to support CYP participation in research' [FG.4]. In addition, participants emphasised that since children in CPS meet many specialists, talking to a researcher could create undue pressure on the children. One participant added: 'We are working with the most vulnerable children,

and we have the children at the bottom of the pile, so naturally, it would be mostly a grey area asking them to participate in research' [FG.1]. Another participant emphasised this, saying:

> Because very often these children are in such vulnerable positions and just, oh, yes, just they have so much on their plate, working through their problems, having realisations, and trying to get a foothold in life, I am not sure [FG.1].

Participants in another group discussed that researchers should realise that getting support from CPS can be sensitive in a small community. They maintained that the researcher was getting much information just by receiving permission to contact a family or a child. One participant said: 'You are also getting information about why this child is here. So, you are already getting a lot of information before you even meet the child' [FG.4].

Interestingly, although it was still noticeable, the discussions in the 2023 focus groups reflected less concern about the risks of participation for children than the focus groups from 2016 and 2019. Participants in the 2023 focus group discussed the importance of allowing CYP to express themselves but stressed that researchers must do it carefully. They noted that CYP, such as CYP in foster care, often lack access to a safe space and the opportunity to express themselves.

Using reports from CPS instead of talking to CYP

In two of the focus groups, the participants discussed the significance of research with CYP but also raised concerns about involving vulnerable children in CPS. They discussed the possibility of doing research differently. They suggested that researchers could gather more information from available working notes written by social workers who know the child in CPS with knowledge and appropriate skills and assessment reports than from talking directly to CYP. By analysing available reports and working notes: '[it] should often be possible to get even more information than talking to the child' [FG.1]. In another focus group, the participants discussed that the researcher should talk to: 'child protection children that are now adults' [FG.1], as they thought the children in contact with CPS often do not have much to say.

The participants' understanding of their role as gatekeepers

Two themes appear in the participants' discussion on their role as gatekeepers: (1) whether it was the participants' role to open the gate and (2) when to open the gate.

'Is it my role to open the gate?'

It is important to emphasise that only one participant across all the focus groups had experienced assisting a researcher in accessing children under the age of 18 for interviews. This participant, who had worked in a child protection agency for over twenty years, talked about one or two such requests in her work life. She said finding children for the interviews had been complicated and time-consuming. Other participants spoke about their experiences in getting adults for interviews or discussion about access to service users (sometimes including children) for research purposes. Therefore, the conversation revolved around their opinions rather than their experiences. One participant talked about rumours in the workplace about the unclear requests from researchers, the lack of information about the benefits to the workplace and whether participants would participate in the research. They said, for example, that it should be clear what the practitioners would gain from assisting the researcher and what the research participants would gain from participating. One participant said, 'It is not just a question of how you might benefit, but also what the other children gain by participating' [FG.4].

Focus group participants discussed that they would refuse to contact parents if their relationships with them were complex, as small issues could significantly disrupt their lives in such cases. One participant said, 'This is a group that does not answer the phone' [FG.4]. Consequently, they would always opt to contact individuals with whom they had the best relationship and who were likely

the most satisfied with the service. This preference could potentially skew the findings, as noted by one participant:

> If I am asked to find children for a researcher to talk to, then I would always look for children who are standing strong … ; those are not the children that are the most vulnerable, so by doing that, we have probably skewed the data [FG.1].

In another focus group, the discussion reflected that they considered children mostly too vulnerable to participate in research and felt compelled to protect them. One participant stated, 'Some children are at such a place mentally that they would not endure some one-hour interview with someone' [FG. 2].

Another group agreed with one participant who said: 'You know these are children I want to safeguard' [FG.1]. In a third group, the participants emphasised that they were working with an especially vulnerable group, 'Children are a vulnerable group, but here you have a group of children that are more vulnerable than average' [FG.3]. Participants in all the focus groups discussed how requests to assist researchers added to the already considerable pressure and stress of their jobs and that they were likely to avoid prioritising such requests. They underscored that it was time-consuming to search for children that would match the researchers' criteria. One participant said, 'Names do not pop up in one's mind immediately, so you just have to think, what child was that? This takes some time, you know' [FG.1].

The participants discussed that serving as a gatekeeper should be someone else's responsibility. They pointed out that it should instead be a manager's role to assist researchers because they are not in direct contact with service users, allowing them 'to get a little more distance' [FG. 4]. Since managers were usually not connected to the cases, their position would be less sensitive towards the service users.

When should the gate be opened?

When the discussion turned towards what must be done for the participants when opening the gate, issues arose regarding the researchers' backgrounds, research topics, and objectives. Participants expressed their preference to assist competent researchers from universities, as opposed to researchers from non-governmental organisations with undefined work qualifications. They said, 'You would not want just anyone to come along' [FG.5]. One participant stated that there was more reason to trust researchers 'from a university that followed legal requirements of the Data Protection Act' [FG.5]. A participant in another group said they would trust a researcher who had been through the process of acquiring permission from the Ethical Scientific Committee.

More participants said they would like to investigate the researchers' backgrounds. They expressed a desire to know if the researchers knew how to talk to children, noting that even though a person from the university might be intellectually clever, it did not necessarily mean they were good at communicating with people. The participants expressed that they would be more willing to help and find a solution to grant access if they knew the researcher and if the researcher was well-qualified. One participant said, 'I think you would be more likely to help people you already know, and it just feels natural for me to find a solution' [FG. 1]. Another participant added, 'Unless you know this person from a bad experience, you know' [FG. 1]. Another focus group discussed that as gatekeepers, they felt it important to meet the researcher to discuss the project and then assess whether the child's safety is guaranteed by participating. One said, 'If I meant to suggest some children, I would want to meet the researcher and review what the discussion with the child would be about' [FG. 2]. Another focus group repeated this view, referring to credibility, trustworthiness and the importance of the researcher's experience and skill in talking to children. One participant stated, 'If you are good at talking to children, then you are also good at talking to adults, but it is much more complicated to communicate with children than adults' [FG. 3].

The participants pointed out that researchers working with CYP should know how to use different communication methods and allow time to understand CYP fully. Some CYP are incredibly open and talk a lot, while others speak less, and it could take time to gain their trust. The researchers should be ready to meet the CYP in a safe place and 'not drag them into some institution' [FG. 3]. If the researcher had a background in social work or was a social worker, they seemed trustworthy to some of the participants. In one focus group, the participants said it would increase credibility and trust 'if the researcher had a background as a social worker' [FG. 4].

Whilst some participants said knowing the researcher's background was imperative, others said it was at least as vital for them to understand the research topic. One said, 'I would not so much think about who the researcher was. It would be more about what is being researched' [FG. 1]. In other focus groups, the discussion was similar; the participants said it would be crucial for the research plan to be clear and that they could see the documents the researcher was using. This way, they could evaluate whether the research project was worth supporting.

Discussion

The main findings suggest that some social workers in CPS find it challenging to support the rights of CYP while simultaneously protecting them from harm. Several participants doubted whether the CYP they care for should participate in research due to their vulnerability. They questioned the researchers' ability to assess CYP's capacity to participate in research interviews.

Regarding their role as gatekeepers, some social workers thought their superiors should complete the selection of CYP participants. Others felt the researchers could achieve the same goals by reviewing available case files or by speaking with adults who, as a child or a young person, had received support from CPS when they were younger.

Finding a balance between a child's participation and protection

The social workers were largely aware of the UNCRC and CYP's right to participate. However, they argued that children in contact with CPS were an exception to CYP in general due to their vulnerability and need for protection. This perspective suggests that the participants prioritised safeguarding CYP over creating opportunities for their participation in a broader sense. Consequently, it appears that the participants were hesitant to grant CYP the autonomy and power to decide for themselves whether or when to participate, which aligns with the findings of Tunestveit et al. (2022).

The discussions across the focus groups were generally consistent, except focus group FG.5, which we interviewed last in 2023 (post-Covid) FG.5 demonstrated greater awareness of children's right to express themselves in research, highlighting a shift in emphasis towards children's rights within professional social work. While the discussions reflected caution among participants, some also expressed a willingness to explore solutions enabling the CYP they worked with to participate in research, recognising its necessity. The discussions suggest a growing interest in and understanding of the importance of CYP's direct participation in research. Some social workers contended that they could adequately represent CYP's rights to participate without CYP meeting researchers directly, thus revealing a lack of clarity or uncertainty about the meaning of CYP participation. Children's rights appear more symbolic than legally enforceable (UNCRC, 1989). Pölkki et al. (2012) defined meaningful participation as a process where CYP can participate, express their opinions on matters that affect them, and contribute to shared goals based on mutual respect.

The participants expressed worries that researchers overemphasised children's rights and that support from childcare authorities is more helpful than research on strengthening the position of vulnerable children.

All focus groups discussed the need to protect children. The participants suggested that supporting CYP's participation in research can be the opposite of protecting them. This finding aligns with earlier

research about the tendency within welfare systems to overprotect marginalised CYP with a 'we know best' attitude instead of finding the concepts cohesive (Kosher & Ben-Arieh, 2020; Kristinsdottir & Arnadottir, 2015; Skelton, 2008; Tunestveit et al., 2022; Van Bijleveld et al., 2015; Vis et al., 2012).

The social workers' attitudes imply that children as participants do not enjoy their legal rights because they do not get the opportunity to participate in research aiming to improve the understanding of their situation and enhance their lives and the lives of other children in similar conditions. When gatekeepers hinder CYP from participating in research, CYP lose the opportunity to present their unique personal experiences, and their voices become silent. Our findings correspond with findings from several other studies (Cossar et al., 2016; Daley, 2015; Heimer et al., 2018; Kennan & Dolan, 2017; Tunestveit et al., 2022; Woolfson, et al., 2010).

In four of the five focus groups, the participants expressed the view that researchers should not interview CYP in contact with CPS. Their ideas of children were in line with previous ideas that children receiving support from CPS need to be protected, seeing them as *becoming* rather than *being* (James et al., 2012; Qvortrup, 1994). Group discussions mostly centred around protecting these children from the potential pressure and damage of participation in research about their reality. The participants stated that children are susceptible and subject to much pressure and that professional practitioners' role should be to protect these children and shield them from unnecessary pressure. The practitioner's attitudes can exclude these children from research participation and thereby prevent their opportunity to use their experience to become empowered and strengthen their position as members of society (Kosher & Ben-Arieh, 2020; Tunestveit et al., 2022; Van Bijleveld et al., 2015).

The social worker's role as gatekeeper

In all focus groups, the discussion reflected the view that practitioners should not have the role of gatekeepers. They said practitioners did not have enough time to work on these concerns. Due to personal privacy legal framework requirements, searching for research participants could take a long time. This finding aligns with other research on the views of professional practitioners helping academics (Moore et al., 2021; Powell et al., 2020).

The social workers said they had heard from colleagues that applications from researchers had detailed requests and that researchers were usually searching for a particular group of participants. They said it would be tough for them to find and ask for permission from that group to participate in research. On the other hand, in the same discussion, they criticised the vague and unclear requests they received from researchers. This inconsistency is also found in earlier research describing participants' experience of poorly conceived and executed research plans (Martins et al., 2018; Powell et al., 2020; Vaswani, 2018).

Interestingly, only one participant across all groups had experienced locating and facilitating CYP's participation in a research project. It is still uncertain whether discussion about the challenges of accessing CYPs for research dissuades researchers from involving them in studies. Alternatively, if gatekeepers consistently deny access, researchers´ requests may never reach CYP and families affiliated with CPS.

Limitations

The participants had a lot to say, even though only one had experience assisting researchers in obtaining access to CYP. This fact raises the question of whether the target group in this research was suitable. Generalising the research is impossible; therefore, the results only reflect the participants' experiences. We planned to finish the interviews in 2020, but because of the COVID-19 pandemic, we conducted one interview in 2023. The fact that the interviews took place over seven years is both an advantage and a limitation.

Conclusion

The participants generally recognised the importance of researching their services but did not view the direct participation of children as necessary. They argued that, due to the vulnerability of CYP in the service, participation in research would be overly complex and challenging for them. Instead, they suggested that researchers could gain insights into CYP's perspectives by reviewing available case files or secondary data already accessible at CPS, or by speaking with adults who had previously received support from CPS as CYP. This perspective suggests that the social workers prioritise a protective mindset, potentially at the expense of CYP's right to participate in research.

The participants considered the CYP in CPS particularly vulnerable and often living in challenging situations. Because of this, the additional pressure of participating in research could be difficult or even damaging. The participants expressed that being a gatekeeper should be a superior's role rather than the role of a practitioner working directly with CYP and their families. They mention several reasons for this. First, they do not have the time to complete these tasks because of heavy workloads. Second, contacting people and asking them for permission to participate in research could damage their working relationship with children and their families.

It is crucial to balance respecting CYP's rights to participate in research and ensuring their right to protection. Achieving this balance enables CYP to feel supported, recognised, and included in decisions that affect their lives. To foster this balance, researchers must prioritise transparency and invest more time in building trusting relationships with social workers and other gatekeepers, demonstrating their knowledge, skills and experiences working among CYP. Additionally, researchers should explain how they will safeguard CYP's well-being during participation and ensure that the research outcomes benefit CYP both now and in the future.

When the emphasis on protection becomes too great in work with children and young people, and their opportunities to participate in research are limited, they risk becoming invisible—their voices unheard and their experiences overlooked.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Hervör Alma Arnadottir, PhD student, Menntavísindasvið Háskóli Íslands og dósent við Félagsráðgjafardeild Háskóla Íslands. Hennar áherslur í rannsóknum eru á bernskufræði, þátttökubarna, þverfaglega teymisvinnu og hópmeðferð.

Sissel Seim, emerita við Oslo Metropolitan University. Hennar áherslur í rannsóknum eru bernskufræði, sameiginleg og einstaklingsmiðuð þátttaka, félagslegar hreyfingar og aðgerðir, vísindakenningar og félagsleg efnishyggja.

Guðrún Kristinsdóttir, er prófessor emerita, á menntavísindasviði Háskóla Íslands. Hennar rannsóknir fjalla um eigindleg rannsóknaraðferðafræði, börn og samfélag, bernskufræði, gagnrýnin kynjafræði, ofbeldi gegn börnum og í nánum samböndum, svo og heimilisofbeldi.

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Paper IV

Chapter 9

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

Hervör Alma Árnadóttir and Martha María Einarsdóttir

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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Appendix

Introductory Letter,

Introductory Letter: Access to Research Field

Subject: Request to Join Focus Group

About me/researcher and what is the purpose of the study?

My name is Hervör Alma Árnadóttir and I am a doctoral student at the School of Education at the University of Iceland. I am currently in the process of gathering data for a study that focuses on children's participation in research. The data will be used to shed light on your experiences with making field research more accessible to scholars, especially in relation to children's research participation. My supervisor is Dr. Guðrún Kristinsdóttir. This letter is intended as an invitation for you to take part in a group interview given your experiences with the subject matter at hand.

I will conduct the interviews with the aid of an assistant who will manage the recording of the interviews. The assistant is free to contribute to the interviews with questions and comments.

What are focus group interviews?

The use of focus groups as a means to collect research data has grown considerably in recent years. Focus groups are considered well suited in cases where a researcher seeks to explore diverse perspectives or opinions concerning a specific phenomenon. The method can be used to encourage dialogue between individuals who e.g. share a common experience. In the discussions, an emphasis is placed on a particular theme or subject matter - which in the current context revolves around access to research fields. The purpose of focus groups is, among other things, to explore differing perspectives and opinions on a specific issue. You will be invited to participate in discussions, suggest a particular topic and analyse the themes that emerge in the discussions. We are interested in your input and your experience regarding access, and I hope that the process will give rise to lively conversations. It is important to bear in mind that there are no right or wrong answers to the questions that the participants are invited to engage with, especially given the fact that the aim is to stimulate discussions in the group rather than answering questions.

What does participation in a focus group entail?

There will be four to six participants in this focus group, along with one leader and one assistant. The interviews will be recorded. An interview will last an hour and a half at most. You will be asked to discuss a particular topic which is related to your role in and experiences with assisting researchers access a given research field. The questions will be connected to your perspective on the topic. You are welcome to discuss personal views on the topic if such a need arises.

When is the focus group scheduled?

One of the challenges of this method is the process of bringing people together. If you are incapable of attending at the scheduled time, please contact me, Hervör Alma, by phone: 8978722 or via email: hervora@hi.is

What happens in the interview?

You will be asked to introduce yourself when you arrive. Following this, we ask you to read over and sign the consent form confirming your participation in the study. You will be provided with a copy of the consent form. We will then describe the interview process, and you are welcome to ask questions if something remains unclear to you. We present the rules to participants, e.g. offering everyone a chance to express themselves and respecting the opinions and emotions of others. The recording equipment will be turned on when everyone is ready, at which the interview commences.

How does participation benefit you?

You will be given the opportunity to participate in a research project where you might gain new knowledge about the research process which could strengthen you as a researcher. In addition, you will hopefully get the chance to participate in lively discussions on issues that you find interesting and that are also significant in a societal context.

Does participation pose any risks?

There are no risks associated with participation in this project. In general, it is worth keeping in mind that the question might give rise to rumination regarding comments or behaviour of other participants. If you are having second thoughts after the interview, please contact Hervör Alma by phone: 8978722 or via email: hervora@hi.is.

Can answers be traced back to participants?

No, the interviews are anonymous and we make sure that answers cannot be traced to any of the participants. We ensure full confidentiality with regard to all information and documents.

Can I withdraw from participation?

Despite having signed consent to participate, you are free to withdraw from the project without explanation for up to 30 days following the completion of the interview. After this period, the interview processing will have reached a stage in which it will prove difficult to separate individual voices from the discussions. In the event that you wish to withdraw, please contact me, Hervör Alma, by phone: 8978722 or via email: hervora@hi.is.

If you have any additional questions please contact:

Hervör Alma Árnadóttir, School of Education, University of Iceland. Email: hervora@hi.is

Respectfully,
Hervör Alma Árnadóttir

Reykjavík, 23 February 2016.

Participant Consent

I consent to participate in a research project regarding the access to research fields. I have been informed about what my participation entails as well as its purpose. I am free to refuse to answer questions and withdraw from the focus group if the situation arises without providing explanation of any kind for my withdrawal. I have been informed that I can withdraw my participation for up to 30 days after the completion of the interview.

I have been informed that confidentiality is ensured and that answers cannot be traced to individual participants. All personal information has been altered or erased. I will not discuss the opinions or conversations that emerge during the interview outside the context of the focus group.

I have been informed that the interview will be recorded and transcribed. I am aware of how the data will be used in this research project which focuses on children's participation in research.

Name:

Signature:

Place/date:

Interview guidelines

Introduction and topic

My name is Hervör Alma Árnadóttir and I am a doctoral student at the School of Education at the University of Iceland. I am currently in the process of gathering data for a study that focuses on children's participation in research. As is well known, studies have emerged over the last decades that show that children can contribute significantly when they are interviewed for research purposes. Moreover, studies have shown that children are willing to participate if they find the research topic important. The data will be used to shed light on your experiences with assisting researchers in gaining access to children for research purposes. My supervisor is Dr. Guðrún Kristinsdóttir.

Please, read the information and ask questions if needed (participants have also received the relevant information via email).

The use of focus groups as a research method has grown considerably in recent years. Focus groups are considered well suited in cases where a researcher seeks to explore diverse perspectives or opinions on a given phenomenon. The method can be used to encourage dialogue between individuals who e.g. share a common experience.

In the discussions, an emphasis is placed on a particular theme or subject matter - which in the current context revolves around access to research fields. The purpose of focus groups is, among other things, to explore differing perspectives and opinions on a specific issue. You will be invited to participate in discussions, suggest a particular topic and analyse the themes that emerge in the discussions. We are interested in your input and your experience concerning access, and I hope that the process will give rise to lively conversations. It is important to bear in mind that there are no right or wrong answers to the questions that the participants are asked to engage with, especially given the fact that the aim is to stimulate discussions in the group rather than answering questions.

Confidentiality/consent form: Explain confidentiality and ask for signature confirming consent.
Ask for permission to start the recording.

Interview framework:

- Invite participants to introduce themselves, state their name, their positions within the institution and to give a brief description of their role in facilitating research as well as their understanding of permission and access.
- Can you describe the process that is initiated when researchers request permission to begin their study and your assistance in gaining access?
- Forms?
- Contracts?

- What is the view towards research in your workplace?
- Is the researcher encouraged to study themes related to the workplace?
- Have those studies proved useful?
- In what way?
- Is there a process in place regarding the presentation of findings from the studies that you have assisted with?

- What is your experience with aiding researchers in gaining access?

- What was successful? Example?
- What went badly? Example?
- Do you know or can you picture how long the process from request to permission usually takes on average?

- What aspects are important in relation to the researcher?
- Perhaps some follow-up questions, such as
- Background?
- Is it important that you are familiar with the researcher's work?

- Sensitive groups, how are these defined in your workplace?
- What does a sensitive group consist of?
- How do you define a sensitive group?

- What is the policy (is there a policy?) in your workplace concerning the process of offering access to children?
- What is your opinion of researcher approaching children in their studies?

- Is it advisable to increase the active participation of children in research?
- What can be done to achieve this?

- Anything you would like to add in closing, any further questions?

Thank you for your participation