Enacting Occupation-Based Transformative Research through Participatory Filmmaking with Children with Disabilities

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A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy  
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Abstract

Occupational science is striving to become a transformative and international science that seeks to address occupational injustices locally and globally. Moving forward in these directions involves expanding beyond Western perspectives on occupation and utilizing critically-informed participatory methodologies. The intent of this dissertation was to enact an occupation-based transformative agenda through a critically-informed participatory action research (PAR) project with children with disabilities from rural South India.

This dissertation is comprised of five integrated manuscripts, as well as introduction and discussion chapters. The first manuscript critically explores the application of the occupational justice framework in research and highlights dominant tendencies, absences, and recommendations for research addressing occupational justice. The second manuscript describes and considers the utility of three participatory digital methodologies (digital storytelling, participatory video/filmmaking, and participatory geographic information systems) for transformative occupation-based research with children and youth. The third manuscript describes the PAR process used with children with disabilities, which employed participatory filmmaking as a research methodology, highlighting different project phases, activities carried out, challenges faced, and strategies used. The fourth manuscript highlights the role of critical reflexivity in addressing ethical tensions in the field by presenting transparent accounts of reflexive notes from facilitators as well as child co-researchers. The fifth manuscript presents the findings from the PAR through participatory and theoretical analyses informed by critical occupational science and critical disability perspectives. The participatory thematic analysis, which was completed in collaboration with children with disabilities, explicates issues of occupational injustices, ways injustices are shaped by context, and how occupations impact context. The theoretical analysis of information gathered with children with disabilities as well as parents, teachers, and service providers, further explicates the situatedness of the injustices expressed by children. This manuscript also highlights types of transformation addressed and occurring through this work.

Overall, this dissertation explicates nuanced understandings on occupation, occupational justice, and disability, through perspectives from the Global South. It contributes to
methodological and theoretical developments within critical occupational science scholarship, as well as highlights implications for educational policy development addressing issues of inclusion and occupational justice within a rural Indian context.

Keywords

occupational justice, participatory action research, inclusive research, participatory videos, critical disability perspectives, global health
Summary for Lay Audience

This dissertation is located within occupational science, a discipline focused on the study of occupation, a term that encompasses the range of everyday activities that individuals and social groups want and need to do. Researchers in occupational science have encouraged projects that address the everyday occupational injustices that individuals and communities face. Specifically, the intent of this project was to work towards addressing the occupational injustices experienced by children with disabilities from a rural village in Southern India by working with them as co-researchers. A participatory action research (PAR) approach was used to work towards equitable collaboration with children with disabilities in all aspects of the research, and in addressing social change. Participatory filmmaking was used as a research methodology. As co-researchers, the children created a group film focused on issues impacting their participation in occupations and social issues in their community they deemed as requiring change. This filmmaking process helped child co-researchers identify issues of injustices, explore what contributed to such injustices, and mobilize change through proposing potential solutions.

This dissertation has five manuscripts, and introduction and conclusion chapters. The first two manuscripts build the foundation for the PAR by exploring the usefulness and application of a theoretical framework and research methodologies relevant for this work. The third and fourth manuscripts describe the participatory filmmaking process used with children with disabilities by highlighting the different project phases, activities carried out in each phase, challenges faced, and strategies used. The last manuscript presents the results from this PAR through an analysis carried out with child co-researchers, as well as another layer of analysis using theory as an analytical lens with additional perspectives from parents, service providers, and community members. The results highlight the injustices that children with disabilities faced in terms of their exclusion from occupations, as well as community concerns related to violence, substance abuse, and environmental degradation. The results increase understanding of how these injustices and concerns were shaped by environmental factors, like economic, cultural, and socio-political systems. This manuscript also highlights how social change has and is being addressed through this work.
Co-Authorship Statement for Manuscript 1


I, Tanya Elizabeth Benjamin, acknowledge that this published manuscript in the *Australian Occupational Therapy Journal* has emerged out of collaborative endeavors. I am the first author for this manuscript and all primary intellectual contributions were made by me, solely contributing approximately 80% by conceptualizing the topic, researching the methodology, designing the research, conducting literature reviews, leading the data analysis and interpretation, and leading the writing of the manuscript. The contribution of co-author, Prof. Debbie Laliberte Rudman, was primarily through supervision of the research, theoretical and methodological guidance, reflexive dialogue and intellectual and editorial support in crafting the work for publication.
Co-Authorship Statement for Manuscript 2


I, Tanya Elizabeth Benjamin, acknowledge that this published manuscript in the *Journal of Occupational Science* has emerged out of collaborative endeavors. I am the first author for this manuscript and all primary intellectual contributions were made by me, solely contributing approximately 70% by conceptualizing the topic, researching the methodology, designing the research, conducting literature reviews, leading the data analysis and interpretation, and leading the writing of the manuscript. The contribution of co-author, Prof. Debbie Laliberte Rudman, was primarily through supervision of the research, theoretical and methodological guidance, reflexive dialogue and intellectual and editorial support in crafting the work for publication. The contribution of co-authors, Dr. Debra Cameron and Dr. Beata Batorowicz, was primarily through methodological guidance, reflexive dialogue, review of data analysis, and editorial support.
Co-Authorship Statement for Manuscript 3


I, Tanya Elizabeth Benjamin, acknowledge that this manuscript under review in *Methodological Innovations* has emerged out of collaborative endeavors. I am the first author for this manuscript and all primary intellectual contributions were made by me, solely contributing approximately 80% by conceptualizing the topic, researching the methodology, designing the research, conducting literature reviews, developing the ethics application, establishing relationships with collaborators, leading the translation and the transcription process, leading the data analysis and interpretation, and leading the writing of the manuscript. The contribution of co-author, Prof. Debbie Laliberte Rudman, was primarily through supervision of the research, theoretical and methodological guidance, reflexive dialogue and intellectual and editorial support in crafting the work for publication. The contribution of co-authors, Mr. Jeshuran Gunaseelan, Prof. Vinod Joseph Abraham, and Mr. Samuel Prasanna Vinoth Kumar, was through supporting data collection, reflexive dialogue, and editorial support. The contribution of co-authors, Dr. Debra Cameron and Dr. Colleen McGrath, was primarily through theoretical and methodological guidance, reflexive dialogue, and intellectual and editorial support.
Co-Authorship Statement for Manuscript 4

Benjamin-Thomas, T. E., Laliberte Rudman, D., & Gunaseelan, J. (pending submission). Navigating ethical tensions through critical reflexivity: A participatory filmmaking project.

I, Tanya Elizabeth Benjamin, acknowledge that this manuscript that is pending submission has emerged out of collaborative endeavors. I am the first author for this manuscript and all primary intellectual contributions were made by me, solely contributing approximately 80% by conceptualizing the topic, conducting literature reviews, leading the data collection, leading the transcription process, leading data analysis and interpretation, and leading the writing of the manuscript. The contribution of co-author, Prof. Debbie Laliberte Rudman, was primarily through supervision of the research, theoretical and methodological guidance, reflexive dialogue and intellectual and editorial support in crafting the work for publication. The contribution of co-author, Mr. Jeshuran Gunaseelan, was primarily through supporting data collection, analysis, and interpretation through reflexive dialogue.
Co-Authorship Statement for Manuscript 5

Benjamin-Thomas, T. E., Laliberte Rudman, D., Cameron, D., McGrath, C., Abraham, V. J., Gunaseelan, J., & Vinoth Kumar, S. P. (pending submission). Issues of occupational justice prioritized and explicated by children with disabilities from rural India.

I, Tanya Elizabeth Benjamin, acknowledge that this manuscript that is pending submission has emerged out of collaborative endeavors. I am the first author for this manuscript and all primary intellectual contributions were made by me, solely contributing approximately 70% by conceptualizing the topic, conducting literature reviews, developing the ethics application, establishing relationships with collaborators, leading the translation and the transcription process, leading the data analysis and interpretation, and leading the writing of the manuscript. The contribution of co-author, Prof. Debbie Laliberte Rudman, was primarily through supervision of the research, theoretical and methodological guidance, reflexive dialogue, and intellectual and editorial support in crafting the work for publication. The contribution of co-authors, Dr. Debra Cameron and Dr. Colleen McGrath, was primarily through reflexive dialogue and intellectual and editorial support. The contribution of co-authors, Prof. Vinod Joseph Abraham, Mr. Jeshuran Gunaseelan, and Mr. Samuel Prasanna Vinoth Kumar, was through providing input regarding the study design and supporting data collection.
Dedication

To the enthusiastic, caring, and talented children I worked with. You have inspired me to keep doing what I love.

To my parents, mummy and appa, you have sacrificed all that you have for my educational pursuits, and I could not have gotten here without you.

My husband David, your love, kindness, and support got me through this process.
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List of Abbreviations

PAR  Participatory Action Research
WFOT  World Federation of Occupational Therapists
UNICEF  United Nations Children’s Fund
WHO  World Health Organization
CBR  Community Based Rehabilitation
CIS  Critical Interpretive Synthesis
PMD  Powered Mobility Device
PGIS  Participatory Geographic Information Systems
DSLR  Digital Single Lens Reflex
YPAR  Youth Participatory Action Research
Chapter 1

1 Introduction

This dissertation adds to the body of work, in occupational science and more broadly, that contests marginalizing research practices and addresses the need for inclusive research practices with children\(^1\) with disabilities from the Global South\(^2\). In this project, children with disabilities from a rural village in Southern India were collaborated with as co-researchers to explore and address matters affecting them. This work is situated within the discipline of occupational science and responds to disciplinary calls for enacting occupation-based socially transformative agendas (Farias et al., 2019; Farias, Laliberte Rudman, & Magalhães, 2016; Hocking, 2012; Hocking & Whiteford, 2012; Laliberte Rudman, 2014; Laliberte Rudman et al., 2019). In this dissertation, participatory filmmaking is introduced within occupational science scholarship as a research methodology for transformative and inclusive research with children with disabilities (Benjamin-Thomas, Laliberte Rudman, Cameron, & Batorowicz, 2018; Benjamin-Thomas et al., under review). Overall, this dissertation sought to expand existing scholarship, on occupation, occupational participation, occupational justice, and disability, and mobilize transformation, through exploring first-hand perspectives of children with disabilities from the Global South.

Participation in occupation, defined as the range of things people need, want, and are expected to do within the context of their everyday lives (World Federation of Occupational Therapists: WFOT, 2017), has been proposed by occupational scientists and occupational therapists to be a key contributor to individual, family, and community well-being (Law, Steinwender, & Leclair, 1998). As well, the United Nations (2016) has

\(^1\) The term ‘children’ is used to refer to every person below the age of 18 years (United Nations, 1989).

\(^2\) ‘Global South’ (Singal, 2010) is interchangeably used with the term ‘majority world’ (Thibeault, 2006) throughout this dissertation. These terms broadly refer to nations holding shared experiences of colonization as well as economic inequality in terms of poorer living standards and resource availability (Singal, 2010). As well, this term recognizes the Global North as “the exception, the privileged minority” (Thibeault, 2006, p. 159).
highlighted that participation in education, employment, political, civic, and cultural life is central to societal inclusion. However, socio-political, cultural, and economic forces, such as taken-for-granted beliefs, social stigma, poverty, a lack of resources, and policies, can create barriers to occupational participation; and being prevented from such participation is a form of injustice referred to as occupational injustice (Townsend & Wilcock, 2004).

It is recognized that some collectives, more than others, have insufficient opportunities for meaningful occupation (Laliberte Rudman, 2013) and are at a greater risk for experiencing occupational injustices. Children with disabilities are one such collective who often experience occupational injustices by being denied opportunities for meaningful occupation, such as education, vocational training programmes, and other day to day activities at home and in the community (UNICEF, 2013a). This risk for occupational injustices is greater among children from low-income and rural communities, especially within the Global South (WHO, 2011). My doctoral work has been informed by this concern for addressing occupational injustices faced by children with disabilities residing within a community in the Global South.

To address global situations of occupational injustices (Townsend & Wilcock, 2004), numerous scholars within occupational science, such as Hocking, Whiteford, Laliberte Rudman, Farias, and others, have increasingly called for transformative occupation-based research that is critical, reflexive, and in turn, socially responsive (Farias & Laliberte Rudman, 2016; Hocking & Whiteford, 2012; Laliberte Rudman, 2013; Laliberte Rudman, 2014). Further, there has been a heightened awareness of how the understandings and theories of occupation and occupational justice are dominated by Western, Anglophonic, middle-class perspectives (Kantartzis & Molineux, 2011) not shared by the majority world (Hammell, 2011; Ramugondo & Kronenberg, 2015). In turn, there have been calls for international perspectives on occupation (Hammell, 2011; Laliberte Rudman et al., 2008), achieved through global collaborations (Magalhães, Farias, Rivas-Quarneti, Alvarez, & Malfitano, 2019) and methodological pluralism (Molineux & Whiteford, 2011), as means to expand disciplinary boundaries and mobilize socially transformative occupation-based agendas. These calls have further shaped my
interest in exploring diverse ways of knowledge production and legitimization as a means for guiding transformative occupation-based research agendas in ways that are relevant within the majority world.

Consistent with these emerging directions for occupational science, my doctoral research addresses, in part, the call for a critical, transformative, international, and inclusive occupational science (Hammell, 2011; Farias & Laliberte Rudman, 2016; Hocking & Whiteford, 2012; Laliberte Rudman et al., 2008; Laliberte Rudman, 2014). This dissertation embodies critical epistemological values that seek to address emancipation of collectives experiencing situations of injustices by challenging the status quo; acknowledging the role of unequal power structures in shaping injustices; and addressing changes in systems that inform and perpetuate injustices (Crotty, 1998; Ponterotto, 2005). Moreover, this work attends to diverse perspectives on occupation from a community in the Global South through utilizing participatory filmmaking as a research methodology (Gubrium & Harper, 2013; Mitchell, Milne & de Lange, 2012). Participatory filmmaking is as an emerging and creative methodology that has not been widely utilized within occupational science. In this dissertation, participatory filmmaking has been utilized to facilitate inclusion of children with disabilities as co-researchers as a means to guide nuanced understandings of occupation from a non-Western perspective, namely, from perspectives of children with disabilities from rural India.

I begin this chapter with a brief introduction on language and key concepts used within this dissertation. I then situate myself within this work by sharing my paradigmatic values, my relationship to this research topic and research context, and my disciplinary location. This is followed by information contextualizing my thesis project with a literature review on the topic of focus, and description of theoretical underpinnings, research approach and methodological choice. I then present the rationale and purpose for this work, and end with my plan of presentation and a summary.

1.1 A Clarification on Language

This dissertation has been written up in an integrated manuscript style to allow for earlier dissemination of the work as well as for me to engage in the process of writing scholarly
publications during the course of my PhD education. In turn, it is important to note that the manuscripts were written up for publication in different journals and the choice of words and style of writing varies accordingly. For instance, chapter two addresses an occupational therapy audience, chapter three an occupational science audience, and chapter four and chapter five a methodology or qualitative research audience. Additionally, in chapters one and seven, I have used personal pronouns, such as ‘I’ or ‘my’ to reflect my role as the primary researcher for this work that has been informed by my personal interests and experiences. However, I use plural pronouns such as ‘we’, ‘us’, ‘our’ in chapters where I am the lead author but where my supervisor, advisory committee, and local co-investigators, have contributed in varied ways in shaping the published work (see statements of co-authorship).

1.2 Key Concepts

The key concepts that have particular prominence within the scope of this dissertation have been defined and addressed in detail in different sections of this dissertation. However, there are a number of other terms used which also require some clarification and in Table 1, I provide a list of key terms with their supporting definitions.

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupation</td>
<td>The range of things people need, want, and are expected to do within the context of their everyday lives (World Federation of Occupational Therapists: WFOT, 2017).</td>
</tr>
<tr>
<td>Occupational Participation</td>
<td>The involvement of individuals, or collectives, in everyday life activities (Law, 2002) that is shaped and negotiated within specific socio-political, cultural, and economic forces that determine the possibilities and limits to involvement (Townsend &amp; Wilcock, 2004).</td>
</tr>
<tr>
<td>Occupational Injustice</td>
<td>When participation in occupation has been “barred, confined, restricted, segregated, prohibited, underdeveloped, disrupted, alienated, marginalized, exploited, excluded or otherwise restricted” (Townsend &amp; Wilcock, 2004, p. 77).</td>
</tr>
<tr>
<td>Occupational Science</td>
<td>A multidisciplinary field focused on the study of ‘occupation’ (Yerxa et al., 1989) to serve as a knowledge base for the occupational therapy profession as well as a means to address social injustices and enact societal reform (Molke, Laliberte Rudman, &amp;</td>
</tr>
</tbody>
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Occupational Therapy | A health profession concerned with promoting health and well-being through the use of occupation (WFOT, 2017).
---|---
Children with Disabilities | Every individual below the age of 18 (United Nations, 1989) with “physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UNICEF, 2007, p. 2).
Global South | Refers to nations holding shared experiences of colonization as well as economic inequality in terms of poorer living standards and resource availability (Singal, 2010). This term is used interchangeably with the term ‘majority world’ that recognizes the Global North as “the exception, the privileged minority” (Thibeault, 2006, p. 159).
Critical Paradigm | A research paradigm within which one views injustices as a consequence of unequal power structures; challenges the dichotomy between knowledge generation and action; questions and challenges the status quo; and seeks to change systems that perpetuate injustices for collectives experiencing marginalization (Crotty, 1998; Ponterotto, 2005).
Participatory Action Research (PAR) | An approach to research that embodies central tenets of equitable participation and social transformation (Benjamin-Thomas, Corrado, McGrath, Laliberte Rudman, & Hand, 2018). Specifically, community members are included as co-researchers in all phases of the research process as means to explore issues that matter to them and enact social transformation through addressing contextual forces creating situations of injustices. This approach goes beyond understanding and raising awareness of a social problem to taking steps towards addressing social change/transformation (Fine & Barreras, 2001; Meyer, 2000; Schwandt, 2001).
Participatory Filmmaking (or Participatory Videos) | A research methodology that embodies a collaborative process where community members use cameras to document, explore, and critically engage with social issues through the process of creating a film that communicates information, reveals hidden social relations and stimulates collective action (Gubrium & Harper, 2013; Mitchell, Milne & de Lange, 2012).
1.3 Situating Myself within this Dissertation

1.3.1 My paradigmatic position

A ‘paradigm’ refers to a set of collective beliefs and values held by researchers that informs how they view reality (i.e., ontology), come to know reality through the nature of relationship between the knower and would-be knower (i.e., epistemology) and, go about understanding reality (i.e., methodology) (Guba & Lincoln, 1994). Carpenter and Suto (2008) argue that it is important for researchers to begin their inquiry by examining their paradigmatic position as paradigmatic values inform which topics are selected and what methodologies and methods are appropriate to employ within a research project. My dissertation is situated within the critical paradigm, within which I view injustices as a consequence of unequal power structures and seek to challenge the dichotomy that exists between knowledge generation and action (Crotty, 1998; Ponterotto, 2005).

The ontological orientation of a critical paradigm is ‘historical realism’ where reality is seen as constantly changing over time, shaped by various contextual forces including socio-political, cultural, economic, ethnic, and gender values (Guba & Lincoln, 1994). Specifically, researchers embodying this ontological stance seek to challenge the status quo and expose and address existing socio-politically created issues related to power and justice with an agenda for social action and emancipation of the oppressed (Carpenter & Suto, 2008; Ponterotto, 2005; Crotty, 1998). Within the context of this dissertation, I have come to perceive, based on my experiences in practice as an occupational therapist, that children with disabilities in rural India often face situations of occupational injustices that are created and shaped by economic, socio-political, cultural, and historical forces. Many families residing in rural parts of India struggle for survival irrespective of whether their household has a child with disabilities, and families with children with disabilities find it even harder to provide for their childrens’ needs (Ghai, 2001). Socio-cultural stigma and a lack of awareness about disability contribute to situations of exclusion experienced by children with disabilities (George, Norman, Benjamin & Mukherjee, 2014; Gupta & Singhal, 2004; Singal, 2010; Wolbring & Ghai, 2015). Policies established for children with disabilities require children with disabilities to have a disability identity card to avail themselves of social welfare, which implicitly marginalizes them as ‘not normal’ and
inherently dependent. Therefore, in taking this ontological stance of historical realism, the status quo regarding children with disabilities within this context, that is, their assumed lack of need or capability to participate in occupations, is seen as needing to be challenged; with simultaneous efforts needed to mobilize action to address contextual forces shaping occupational injustices.

The epistemological stance within the critical paradigm is seen as ‘transactional and subjectivist’ (Guba & Lincoln, 1994). Within this stance, the researcher is not considered separate from the researched, and researcher values have an influence on the research tasks, purpose, methods, and results (Ponterotto, 2005). Specifically, the relationship between myself, the researcher, and children with disabilities, the co-researchers within this project, is transactional. To address this transactional relationship, I engaged in a process of self-reflexivity and shared reflexivity with my co-facilitator and child co-researchers in the field, as well as with my supervisor. This reflexive process of engaging in explicit self-awareness of how one’s role, thoughts, actions, values, and beliefs, influenced the research process (Finlay, 2002) helped guide ethical research practices (Guillemin & Gillam, 2004; Phelan & Kinsella, 2013). In chapter five, I have discussed and made transparent how individual, and shared reflexivity with my co-facilitator and child co-researchers, played a central role in navigating and addressing ethical tensions in the field.

1.3.2 Situating myself within this research agenda

The purpose of this section is to provide context about what informed my interest in this topic and the specific geographical location of this research. Within critically-informed research, critical reflexivity and positionality is imperative to quality (Whittemore, Chase & Mandle, 2001). Engaging in reflexivity facilitates exploration of how one’s personal experiences and values, informed by socio-political and cultural forces, have an influence on one’s research interests and research processes (Berger, 2015). As Finlay (2002) argues “ideally, the process of reflection and reflexive analysis should start from the moment the research is conceived. As the idea for a project is forming, researchers need to reflect on both the topic for study and their own relationship to that topic” (p. 536).
Therefore, to better situate myself within the context of this dissertation, I critically reflect on my background and experiences in relation to the research topic and context.

I have come to this research topic through my professional practice experiences as an occupational therapist in rural India and my academic interests in critical theory and participatory action research (PAR) approaches. I practiced as an occupational therapist within a community health department of a mission hospital in India, working among approximately 40 rural villages in the outskirts of a city in Southern India. I worked in this position for a period of two years and it was during this time that I became sensitized to how children with disabilities often have very limited opportunities to participate in occupations and often experienced situations of exclusion. As I was the first and only occupational therapist at the time working for the hospital and serving communities across many villages, I tended to focus on the physical and cognitive rehabilitation of children with disabilities. Parents often wanted their child to first attain their physical and cognitive milestones before they wanted to provide them with occupational opportunities, such as schooling. Also, it was during this time that I had the opportunity to organize various occupation-based events and outings for children with disabilities from within and outside of those communities (e.g., group sports activities, picnics, and cultural events). These occupational opportunities were often the first for most of these children, which included their first time to a local park, on a train ride, or even playing with a group of other children. Indeed, it was common for children with disabilities residing in these rural contexts to be excluded from many aspects of their communities with insufficient avenues to participate in occupations. This lack of participation of children with disabilities both within and outside of their homes was due to more than just a lack of awareness from parents. Parents were often struggling to make ends meet, had other children to care for, and also embodied a sense of hopelessness with regard to the prognosis of their child with disabilities in striving for ‘normalcy.’ In turn, their child’s occupational participation was not a priority when they were focused on seeking biomedical forms of treatments (e.g., exercises, medication). Furthermore, schools often denied children with disabilities admission. Even if children with disabilities were admitted into schools there were no resources to support their participation in school activities, which resulted in them being excluded even within the school environment.
Therefore, from my experiences, it appeared common for children with disabilities within the rural Indian context to be excluded from participating in meaningful occupations. The lack of opportunities for meaningful occupation among children with disabilities witnessed during my time in practice always felt like an issue of justice. Especially because participating in varied occupations was extremely important for me as a young woman, and something I enjoyed throughout my childhood. These experiences in practice formed a basis for my research interests that seek to address situations of occupational injustices experienced by children with disabilities.

When I pursued my post professional master’s in occupational therapy, I was introduced to the occupational justice framework (Townsend & Wilcock, 2004; Wilcock & Townsend, 2000), which deeply resonated with me. Eventually, in my first year of PhD education, I conducted an in-depth review of articles to explore how this framework was utilized in research (Benjamin-Thomas & Laliberte Rudman, 2018). When working on this review and analysis I was sensitized to the need for further uptake of participatory and transformative approaches within occupational science. In turn, I explored the utility of emerging participatory and digital methodologies for transformative occupation-based research with children and youth (Benjamin-Thomas, Laliberte Rudman et al., 2018). Additionally, the need for understanding issues of occupational injustices from communities in the Global South was also made apparent through this review, which further propelled my PhD work to be within a community from the Global South.

1.3.3 Situating myself within the research context

In this section, I provide details of how rural India was chosen as a site for this research project, and how I navigated my positions as both an insider and outsider within this context.

1.3.3.1 Contextualizing the process of choosing India as my research context

Although my PhD education is within a Canadian institution, I chose to carry out my research project in India due to various reasons. I grew up in India and spent most of my life there, and as articulated earlier I was witness to many injustices faced by children
with disabilities during my time in practice as an occupational therapist. It was during that time that I was internally motivated to get further training in research, so I could potentially inform and address change at the systems level, as the injustices experienced by children with disabilities were often socio-politically situated. With that in mind, I moved to the United States of America to pursue a post professional Master of Science degree in occupational therapy. Within that program, I was sensitized to the concept of ‘participation’ and also introduced to the ‘occupational justice’ framework while completing a thesis focused on exploring how young children with and without disabilities participated within North American early childhood educational environments. On completing my master’s education, I felt motivated to learn more about different research approaches that could affect social change and address injustices experienced by different collectives. With that agenda in mind, I applied to pursue my PhD in occupational science, and in the first year of my PhD studies, I started exploring research approaches for addressing social injustices and affecting social change. I learnt about PAR and its commitment to inclusion, equity, and justice, both within the research process and as a research outcome (Benjamin-Thomas, Corrado, McGrath, Laliberte Rudman, & Hand, 2018). Delving more into the different methods and methodologies that could be utilized within PAR, I realized that digital methods and methodologies could be used within my PhD thesis project given that these methodologies have the potential to support the participation of children with disabilities within research and also simultaneously work with them towards addressing social change (Benjamin-Thomas, Laliberte Rudman et al., 2018).

While engaging with literature on occupational justice, PAR, and transformative occupational science, I was constantly reminded of why I wanted to pursue PhD studies. This pushed me to explore options to carry out this project with children with disabilities and within a rural Indian context so I could use my skills within a community I was passionate to work with. I then reached out to the institution where I did my undergraduate degree in occupational therapy and explored options for collaboration on this project. Specifically, I was familiar with the villages, the language, and the people within the institution, which created an opportunity for collaboration, an essential part of
the PAR process. Moreover, I also had extended family living in the same city who are extremely supportive, which I envisioned needing during this process in the field.

1.3.3.2 Navigating both insider and outsider positions within the research context

As a PhD student from a Canadian institution, this position automatically situates me as an outsider within the community where this research was carried out. Specifically, this outsider position was reflected in the way I spoke the local language and introduced myself, and also to some extent in the way I might have dressed and the material things I carried with me to the community. However, I am also a citizen of India, with the same mother tongue (i.e., Tamil) as most group members. Although I do speak the local language, I recognize that I come from a different background with different opportunities for education being raised in a city in a middle-class Indian family. Even if I do claim to be an insider because of my familiarity with the language, culture, and context, I am also still an outsider in many ways which meant negotiating both positions throughout the research process (Potts & Brown, 2015). Through embracing these varied positions, I was able to recognize some assumptions I brought to this work, which shaped the research and action processes.

Although I identify myself as an occupational therapist who received my professional degree from India, I recognize that I have primarily learned and engaged with occupational therapy material through books and articles that were published within an Anglophonic, North American, minority world, context. Certainly, there is a dearth of occupational therapy books and publications from an Indian context. In turn, my perceptions about the needs of children with disabilities is based on these educational experiences as well as my practice experiences as an occupational therapist and my upbringing as a middle-class urban Indian woman. The needs I perceive as important and requiring immediate action, may be different from what the communities perceive as important. These tensions further informed the need for me to continually engage in critical reflexivity about my position, values, and assumptions, so I could practice cultural humility (Tervalon & Murray-Garcia, 1998) when working with this community.
1.3.4 Situating myself within occupational science and its transformative turn

My dissertation is situated within the discipline of occupational science, an interdisciplinary field, founded in the 1980s and 1990s. This field is focused on the study of ‘occupation’ (Yerxa et al., 1989), with articulated aims ranging from serving as a knowledge base for the occupational therapy profession to addressing occupational injustices and enacting societal reform (Hocking & Whiteford, 2012; Molke, Laliberte Rudman, & Polatajko, 2004).

The transformative turn refers to a recent movement within occupational science with an increase in uptake of critical perspectives addressing the power of occupation in mobilizing social transformation (Farias & Laliberte Rudman, 2016). To better enact the discipline’s vision for social transformation, scholars in the discipline have critiqued individualistic and postpositive approaches that have dominated the discipline’s scholarship (Hocking, 2012; Kantarzis & Molineux, 2011; Laliberte Rudman, 2013; Townsend, 1997), as “with an individual perspective, one lacks an understanding of institutional inequality as well as the ways in which the sociocultural context constitutes individuals” (Angell, 2014, p. 110). In turn, there is a range of critically-informed scholarship that emphasizes the situated nature of occupation and occupational participation, acknowledging how occupation is socio-politically and culturally shaped as well as pointing to the role of power in shaping what people can and cannot do (Farias & Laliberte Rudman, 2016; Galvaan, 2015; Laliberte Rudman & Huot, 2013; Laliberte Rudman, 2015). Certainly, for occupational science to be a socially relevant discipline, its focus needs to move beyond the individuals experiencing injustices and towards the forces informing such situations of injustices (Angell, 2014; Farias et al., 2016; Farias & Laliberte Rudman, 2016; Galvaan, 2015; Laliberte Rudman, 2012, 2014).

Moreover, the discipline’s scholarship has been critiqued for its narrow understandings of occupation, as it predominantly embodies Western, Anglophonic, white, middle-class,
adult, female, and able-bodied perspectives (Hammell, 2011; Hocking, 2012; Magalhães et al., 2019; Kantartzis & Molineux; 2011, 2012; Pollard, Sakellariou, & Lawson-Porter, 2010). It has been argued that these dominant perspectives tend to homogenize the science and overlook perspectives from the majority world, in turn, reflecting power imbalances and ethnocentrism within the discipline (Hammell, 2011). As Hocking (2012) reminds us, “clearly, such non-critical acceptance of a homogenized science of occupation is problematic” (p. 55). In turn, occupational scientists have been called to embrace diverse perspectives on occupation so this science can thrive as an international science that “will engage in a continuum of knowledge generation and action concerning the construct of occupation, with respect to local and global implications relevant to academia, policy, and the general public” (Laliberte Rudman et al., 2008, p. 136). Indeed, the analysis of occupation from diverse perspectives would promote better understanding of socio-political structures shaping situations of injustices and, in turn, guide social transformation (Angell, 2014; Laliberte Rudman, 2014).

Specifically, the discipline’s scholarship lacks information addressing first-hand perspectives of people with disabilities, especially from the Global South. Hammell (2011) makes transparent this concern by reminding us that “occupational theorists have only rarely sought to explore the needs and perspectives of disabled people in the majority world, and perhaps beliefs, constructs and theories of occupation would look different if we did” (Hammell, 2011, p. 31). More specifically, the perspectives of children with disabilities from the Global South are rarely addressed and remain within the margins of the discipline’s scholarship. As will be detailed, this thesis demonstrates that attending to the perspectives of children with disabilities from the Global South supports expanding the figured world of occupation (Kiepek, Phelan, & Maghalhães, 2014) by challenging dominant notions regarding the constructs of occupation and occupational participation.

1.4 Contextualizing this Thesis

To better contextualize this thesis work carried out in rural Southern India with children with disabilities, I present background information addressing how disability, and research addressing children with disabilities, is situated within an Indian context. This
information serves as a literature review for the dissertation’s substantive topic area by broadly addressing disability within an Indian context, which is in addition to the reviews of literature addressing the theoretical framework on occupational justice and participatory digital methodologies presented as chapters two and three (Benjamin-Thomas & Laliberte Rudman, 2018; Benjamin-Thomas, Laliberte Rudman et al., 2018). To further situate this thesis within a critical paradigmatic location, this background information on disability and disability research in India is followed by an overview of theoretical perspectives informing this work and research approach used.

1.4.1 Situating disability and research addressing children with disabilities within an Indian context

In India, religious and language diversities co-exist with historically situated caste systems and socio-economic divides that make it too complex to be considered a homogenous single unit (Panda & Gupta, 2004). These diverse situations make it imperative for researchers to contextualize their research and demarcate specifics regarding its context and participants involved (Ghai, 2002). A majority of children with disabilities in India are from poorer backgrounds and rural areas (Anees, 2014; Mehrotra, 2011) that make up seventy percent of the country (Chandramouli, 2011). As such, disability has been considered as both a cause and consequence of poverty both in India and globally (Rao, 2009). Due to varied and unreliable estimates on disability in India, the number of children living with disabilities has been presented as a broad range between six million and thirty million individuals (Office of the Chief Commissioner for Persons with Disabilities, 2003, as cited in Singal, 2006). These varying estimates, to some extent, reflect how disability has been prioritized and addressed within the Indian context (Ghai, 2002; Rao, 2009). For example, scholars like Ghai (2002) argue that historically, disability as a social construct has been situated as invisible within the Indian culture that “valorizes perfection” (p. 90), which in turn, has led to situations of marginalization. However, since the late 1980s, there has been growing resistance to experiences of injustices from within groups of people with disabilities, and a simultaneous push from international organizations, which has mobilized change addressing the rights of people with disabilities and contributed to the development of the
Persons with Disability Act in 1995 (Mehrotra, 2011). This act has been recently replaced with The Rights of Persons with Disabilities Act (Government of India, 2016) which aims to promote equal opportunities and full participation of people with disabilities within Indian society.

Despite policy changes, individuals with disabilities in India, including children with disabilities, often experience marginalization which can play out differently based on socio-economic status, location, age, gender, caste and religion (Ghai, 2001, 2002). In spite of India being a multi-religious, multi-ethnic and multi-cultural country (Mehrotra, 2011), literature on disability in India, seems to predominantly link disability related situations of marginalization with the Hindu mythology. According to the 2011 census data, approximately eighty percent of the Indian population practices Hinduism (Office of Registrar General & Census Commissioner India, 2019), and the values, beliefs, and mythologies associated with Hinduism potentially shape Indian culture and, in turn, the social construction of disability.

Within Hindu mythology, disability has been associated with ‘evil’; however, with gendered differences. More specifically, within Hindu scriptures, men with disabilities, although acknowledged as evil, have been portrayed as powerful and wealthy, and in contrast, women with disabilities have been portrayed as evil, ugly, manipulative, and of a lower status (Anees, 2014). Furthermore, situated within Hindu beliefs, ‘disability’ is often associated with the concept of ‘karma,’ seen as a form of retribution for past and present sins (Anees, 2014; George et al., 2014; Singh & Ghai, 2009). At the same time, charitable acts towards people with disabilities are seen as a righteous duty or ‘dharma’ (Anees, 2014), which is reflected in the stance taken by community members who view children with disabilities as needing help or charity. There are also instances, based on varied Hindu beliefs, where children with disabilities are considered as ‘children of God’ (Singh & Ghai, 2009) or with ‘god like powers’ (Lang, 2001) or even worshipped as God (Nelson, 2015), indicating “a dignified negotiation of difference” between children with and without disabilities (Ghai, 2001, p. 27).
Children with disabilities are often seen as needing to overcome limitations with parents holding on to “an illusion of complete recovery” (Ghai, 2001, p. 31), which, if not attained, becomes a defining characteristic of the child as reflected in the different descriptions used to identify them (Wolbring & Ghai, 2015). Specifically, the literal translation of the word ‘disability’ in an Indian language either focuses on specific impairments (Center for International Rehabilitation, 2005; Singal, 2010) or is accompanied by stigmatizing discourses such as ‘lacking abilities,’ ‘tragic loss,’ ‘dependency,’ ‘abnormality’ or ‘poor thing’ (Wolbring & Ghai, 2015). These stigmatizing discourses, coupled with numerous beliefs surrounding disability within an Indian context, create situations of marginalization both for the child as well as for their family members (Anees, 2014; George et al., 2014), which play out in the form of social stigma and shunning of children with disabilities and their families (Richard, 2014). In turn, it is common for children with disabilities to become beggars (Mehrotra, 2011) or be institutionalized in places where they are prone to be abused and isolated, at times, also leading to death (National Disability Network & National Committee on the Rights of Persons with Disabilities, 2017). Even if children are not institutionalized, they experience marginalization and exclusion within their homes and communities (Antony, 2013; George et al., 2014; Gulati, Paterson, Medves, & Luce-Kapler, 2010).

Specifically, children with disabilities are often denied admission into schools with no opportunities for any form of early childhood or preschool education, especially within tribal and rural communities (Ghai, 2001). Even if admitted into schools, they are denied opportunities to participate (Taneja, 2015), partly as a result of insufficient resources to support the needs of children with disabilities within school environments (Anees, 2014). Furthermore, children with disabilities themselves refuse to participate school-related activities due to perceived caregiver social and emotional burden associated with the negative attitudes (Singh & Ghai, 2009) and where their presence is considered unfavorable (Anees, 2014).

In addition, family members battle against socio-cultural forces that blame them (George et al., 2014; Singh & Ghai, 2009), specially mothers, for giving birth to a child with disabilities (Richard, 2014). These socio-cultural forces also shape parents’ perceptions
of disability, which in turn, influence if and how they can provide opportunities for children with disabilities to participate in meaningful occupations (Richard, 2014). In addition to their exclusion within a school environment, children with disabilities are often not expected to participate at home (Singh & Ghai, 2009) and in community activities (Gulati et al., 2010). Thus, socio-cultural forces of stigma and marginalization lead to parents keeping their child hidden from society (Singal, 2010). As such, a birth of a child with disabilities within a family experiencing poverty is considered “a fate worse than death” (Ghai, 2001, p. 29). Additionally, families with a girl child with disabilities consider it as “doubly negative” (Ghai, 2001, p. 35). This intentional seclusion, coupled with the socio-political and economic barriers that prevent children with disabilities from participating at home, school, and the community, largely limits their opportunities for occupational participation, and is considered within this dissertation as an occupational injustice given the links between occupation, health and well-being (Townsend & Wilcock, 2004).

Several global initiatives, such as community-based rehabilitation (CBR) developed by the World Health Organization (WHO: 2010), and established policies and guidelines from the United Nations Children’s Fund (UNICEF: 2013a, 2013b, 2017), embody goals for inclusion, equal rights, and participation of children with disabilities in society. Although such initiatives have, to some extent, mobilized the Indian government as well as non-governmental organizations to address disability related needs, there are still gaps between policies and guidelines that enforce inclusion of people with disabilities and realities that reflect their exclusion in society (Center for International Rehabilitation, 2005). As such, Ghai (2002) has argued that disability related changes in India are often mobilized only for the privileged and the middle-class society. In addition, critics have argued that CBR “clearly reflects the biases of the urban, educated social activists and those of funding agencies” (Mehrotra, 2011, p. 69). Furthermore, international movements have been said to embody western theories “that lack cultural grounding needed for understanding the Indian perspective and perception” (Ghai, 2002, p. 94). As such, power and privilege, informed by socio-economic status and/or location (i.e., urban/rural), have legitimized differences in the experiences of people with disabilities through creating a hierarchy in the construction of social realities for different groups of
people with disabilities (Ghai, 2002). Such hegemonic power relations have prevented the full execution of these global as well as local legislations pertaining to the rights of all people with disabilities, especially within poorer and rural communities (Ghai, 2001).

Disability related services by international non-governmental organizations have historical links with colonialism. Ingstad (2001) highlights that “colonial powers brought with them the principle that assistance to people with disabilities should be financed through fund-raising and private donations and organized by specially committed groups or private persons” (p. 778). In turn, Ingstad (2001) argues that the spirit of charity that organizations embody could also be considered as a reason for the failure of the government to commit to being responsible to provide for the needs of people with disabilities. Furthermore, while India has been positioned as a growing economy within globalization, Ghai (2001) argues that it has “systematically dislodged vulnerable groups from access to even basic resources such as food and livelihood” (Ghai, 2001, p. 26). Therefore, in spite of varied disability debates, initiatives and development efforts within India, children with disabilities, especially those in situations of poverty, are still a marginalized collective experiencing socio-politically constructed situations of occupational injustice.

A majority of research in India with children with disabilities addresses epidemiological and biomedical aspects of impairments, function, and disability (Banerjee et al., 2009; Gardens et al., 2014; Kaur, Thomas, Jindal & Bhatti, 2016; Singhi, Ray & Suri, 2002; Yousafzai, Filteau & Wirz, 2003). Outside these frames, there are examples of research exploring challenges to rehabilitation faced by children with disabilities (George et al., 2014; Gulati, Paterson, Medves, & Luce-Kapler, 2011); caregiver burden, attitude, stress and psychological morbidity (Chandorkar & Chakraborty, 2000; Rangaswami, 1995); and cultural attitudes towards disability (Dalal & Pande, 1999). Overall, research rarely addresses the everyday life experiences of children with disabilities (Wickenden & Kembhavi-Tam, 2014).

Research in India with children with disabilities exploring issues relevant to occupation appears to predominantly focus on education (Bakhshi, Babulal & Trani, 2017; George et
For example, such projects have explored perspectives of teachers, and children without disabilities, on inclusive education (George et al., 2014); parent perspectives about challenges to accessing education that children with autism face (Johansson, 2016); and barriers to education faced by children with disabilities through household surveys (Bakhshi et al., 2017). Singal and colleagues’ (2011) work addressing education of children with disabilities was innovative in its incorporation of the perspectives of young people (aged 15-30 years) with impairments (hearing, visual, and mobility) from urban and rural Central India in exploring the role of education in their lives. These young people shared, through interviews, their experiences in and out of school, the social, economic, and cultural benefits of schooling, their aspirations and expectations in terms of employment, and realities faced addressing unemployment due to socio-political and systemic barriers.

Kembhavi (2009) carried out a mixed methods study to explore the quality of life of adolescents with physical disabilities (aged 13-19 years) residing in a city in Southern India. In addition to the perspectives of parents/caregivers and adolescents without disabilities, the first-hand perspectives of adolescents with physical disabilities were explored. Specifically, their experiences of participation and inclusion were gathered using photography and focus group discussions or individual interviews. The results found that the primary influencers of inclusion and participation included personal factors (i.e., spirituality, feelings about disability, participation in education and leisure activities, and future aspirations), interpersonal relationships with family and friends, and external environmental factors (i.e., physical environment, access, policies and social structures).

Using an occupational lens, Gulati and colleagues (2010, 2011) carried out a critical ethnography to understand how adolescents (aged 12-18 years) with disabilities, from an urban slum in Northern India, could assume greater control over their rehabilitation and community participation needs. This research embodied multiple methods for data collection, such as observations, interviews, focus groups, as well some participatory and creative methods like impact drawings, group tree drawings, and forced field analysis. Adolescents with and without disabilities, and CBR workers, shared and reflected about
disability within their community. Through their activities, they aimed to raise awareness about socio-political and cultural issues impacting the quality of life of adolescents with disabilities, as well as promote their community participation (Gulati et al., 2011). Through this research, a conceptual framework called the ‘adolescent group empowerment pyramid,’ which presents a process for empowering adolescents, was developed. Overall, this framework highlights a desire for adolescents with disabilities within that specific context to engage in meaningful activities with their peers, and to demonstrate, and be recognized for, their abilities within their communities. Beyond the work of Gulati and colleagues (2010, 2011) there seems to be limited research that explicitly explored occupational participation or occupational injustices experienced by children with disabilities within an Indian context.

With regard to whose voices were heard within research specific to the Indian context, it seems to be common for researchers to engage with significant others or service providers of children with disabilities such as parents, teachers, or health care providers, instead of children with disabilities themselves when exploring disability related experiences (George et al., 2014; Johansson, 2016; Yousafzai, Pagedar, Wirz & Filteau, 2003). Key reasons stated for this exclusion of children with disabilities in research extend from dominant socio-political constructed notions of children with disabilities as incapable (Wickenden & Kembhavi-Tam, 2014), to the common use of research methods that do not support the expression and communication needs of children with disabilities (Singal, 2010). As Singal (2010) points out, within the Indian context as well as the Global South, “there is a significant lacuna of research evidence which captures the thoughts, feelings and perceptions of people with disabilities themselves” (p. 420). In turn, scholars have made calls for incorporating children’s perspectives within research addressing disability and related issues (Kembhavi & Wirz, 2009; Singal, 2010). Overall, very few researchers, with exceptions like Gulati and colleagues (2010, 2011), Singal and colleagues (2011), and Kembhavi and Wirz (2009), have attempted to engage with children with disabilities within an Indian context to understand their perspectives about their everyday experiences.
The United Nations Convention on the Rights of a Child in article 12 argues for the democratic participation of all children within decision-making processes concerning them (United Nations, 1989). Therefore, “children with disabilities, like all other children, have a right to express their views freely in matters affecting them” (UNICEF, 2007, p. 20-21). Respecting and including the views of children with disabilities within decision-making processes and research processes is said to lead to better decision making (Lansdown, 2001). Singal (2010), on reflecting on challenges within a research project that aimed to listen to narratives from children with disabilities, makes transparent that one of the greatest challenges was to enable research participants to have greater control of the research process. She, in turn, makes calls for participatory research approaches to be utilized with children with disabilities. Similarly, Singh and Ghai (2009) also articulate that children with disabilities need to be “understood as social actors, as controllers and as negotiating their complex identities within a disabling environment” (p. 132). As such, their involvement within the research and change process can provide them with a space to voice out their perspectives on experiences related to disability, inclusion, and occupational participation. In turn, such space can enable contributing to disrupting the “deeply entrenched ability normative ideals that deprive them of their social presence and any semblance of identity” (Wolbring & Ghai, 2015, p. 669) and drive agendas toward social transformation. Therefore, there is a need for researchers and scholars working with children with disabilities in India to utilize PAR approaches so as to disrupt unequal power relations within the research process and as an outcome of research. This approach to research embodies a means for promoting equitable research collaboration between researchers and children with disabilities and seeks to utilize their knowledge and experiences in facilitating relevant and meaningful social change (Benjamin-Thomas, Corrado et al., 2018). However, such participatory and transformative research approaches with children with disabilities within a Southern context needs to be culturally situated; as they have a potential to import Western agendas of individualism to Southern communities embodying more collectivist values (Singal, 2010).
1.4.2 Situating within a critical paradigm: Theoretical underpinnings informing research approach, methodological choice and analysis

A critical paradigm is a broad umbrella within which research can draw upon varied critical social theories (Farias & Laliberte Rudman, 2016). In this thesis, key principles and concepts from a critical occupational science perspective (Laliberte Rudman, 2018; Njelesani, Gibson, Nixon, Cameron & Polatajko, 2013) and critical disability perspectives (Devlin & Pothier, 2006; Goodley 2013; Hosking, 2008; Meekosha & Shuttleworth, 2009) underpin this work. These principles and concepts played a central role in shaping this work, in terms of informing the research purpose and methodological choice, as well as in shaping how information was analyzed, interpreted, and presented (Finlay, 2002). In this section, I provide a brief introduction of the two theoretical perspectives utilized within the scope of this project, pointing to key principles and concepts drawn from each, which are revisited in chapter six as a lens for explicating and discussing the results gathered from the participatory filmmaking project carried out within this dissertation. Concepts from these perspectives are also integrated into chapter two (Benjamin-Thomas & Laliberte Rudman, 2018) and chapter four (Benjamin-Thomas et al., under review).

1.4.2.1 A critical occupational science perspective

A critical occupational science perspective (Laliberte Rudman, 2018), also referred to as a critical occupational perspective (Njelesani, Gibson, Nixon, Cameron, & Polatajko, 2013), is a specific perspective within the discipline of occupational science that draws from the fields of critical social science and occupational science. This perspective not only acknowledges ‘occupation’ as situated (Molineux & Whiteford, 2011), shaped, and negotiated within various contextual forces and power relations (Farias & Laliberte Rudman, 2016; Gerlach, Teachman, Laliberte Rudman, Aldrich, & Huot, 2018), but also questions power relations informing occupational injustices. Specifically questioning, “why certain occupations persist, whose interests they serve, and the assumptions that underpin their ongoing acceptance” (Njelesani et al., 2013, p. 209-210). Overall, a critical occupational science perspective situates occupational science as socially responsive,
guiding knowledge development in a manner that engages with global issues of social inequity and injustices relevant to occupation (Hocking & Whiteford, 2012). The agenda for social transformation calls for attending to different ways of knowing through methodological expansions (Laliberte Rudman, 2012), as a means to challenge the dominant Western, middle-class, Anglophonic, adult, able-bodied nature of knowledge development within occupational science (Hammell, 2011; Hocking, 2012; Kantartzis & Molineux, 2011, 2012; Magalhães et al., 2019; Pollard et al., 2010).

Informed by this critical occupational science perspective, this dissertation responds to the call for enacting an occupation-based transformative agenda through listening to first-hand perspectives of children with disabilities from a rural village in Southern India and addressing issues that matter to them. Participatory filmmaking, an emerging and creative methodology, has been utilized as a means to strive towards an inclusive research process, and to amplify non-Western perspectives on occupation and occupational justice. This project seeks to question the ‘way things are’ with regards to the everyday experiences of children with disabilities and critically interrogate how occupational injustices experienced by them and their communities are shaped within power relations.

The occupational justice framework can be situated within the critical occupational science perspective. It is predicated on a fundamental premise that participation in meaningful occupations is an individual right and being prevented from such participation is seen as an injustice (Townsend & Wilcock, 2004; Wilcock & Townsend, 2000). The occupational justice framework embodies certain underlying values and assumptions, specifically: all individuals are occupational beings (Stadnyk, Townsend, & Wilcock, 2010), participation in meaningful occupation leads to positive health, well-being, and social inclusion (Townsend & Wilcock, 2004), and participation in occupation is influenced by, and occupational injustices are shaped through, contextual and sociohistorical forces (Stadnyk et al., 2010; Townsend, 2015). When participation in occupations has been “barred, confined, restricted, segregated, prohibited, underdeveloped, disrupted, alienated, marginalized, exploited, excluded or otherwise restricted” (Townsend & Wilcock, 2004, p.77), it is seen as an occupational injustice. The occupational justice framework embodies moral commitments to address forces creating
situations of injustices and to promote equitable opportunities for meaningful occupations (Durocher, Gibson, & Rappolt, 2014; Townsend & Wilcock, 2004; Wilcock & Townsend, 2000).

Within the context of this project, children with disabilities in rural Indian communities are seen as experiencing occupational injustices, in terms of being denied opportunities to participate in meaningful occupations. The occupational justice framework acts as a conceptual frame in supporting identification as well as addressing situations of occupational injustices experienced by this collective. This theoretical framework is addressed in detail in chapter two, where its application in research has been reviewed and critical analyzed (Benjamin-Thomas & Laliberte Rudman, 2018).

1.4.2.2 Critical disability perspectives

Critical disability perspectives is an umbrella term that is used to tie together approaches in disability scholarship that embody a critical approach to the analysis of disability. Specifically, analysis commits to rethinking related assumptions of theory, research, and activism (Goodley 2013), and challenging dominant negative languages, discourses, labels, and images, associated with disability (Hosking, 2008). The commitment to exploring, understanding, and analyzing issues related to disability is driven by intents towards changing disabling relationships (Meekosha & Dowse, 2007) and affecting social transformation (Hosking, 2008; Meekosha & Shuttleworth, 2009). Critical disability theorists argue that “disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion, rather, it is a question of politics and power (lessness), power over, and power to” (Devlin & Pothier, 2006, p. 2). This lens attempts to move beyond the medical model and the social model of disability, conceptualizing disability as an interrelationship between the impairment, an individual’s response to the impairment, and the socio-political context that often fails to meet the needs of individuals with disabilities (Hosking, 2008). As such, disability is seen as one among the many axes of oppression and the “concatenated experience is more than the sum of its parts” (Devlin & Pothier, 2006, p. 14). In my thesis, the first-hand experiences of children with disabilities from a rural village in Southern India seeks to enhance
understandings on the situated nature of disability related experiences shaped by economic, cultural, and socio-political forces.

Critical disability perspectives seek to listen to people with disabilities to understand their first-hand experiences as a means for theory to emerge from the bottom up, “rather than from the top down, from the disembodied ivory tower” (Devlin & Pothier, 2006, p. 6). These first-hand perspectives are central in challenging the taken for granted troubling notions of disability, that position them as ‘dis-citizens,’ and promoting avenues for their participation and genuine inclusiveness in society (Devlin & Pothier, 2006). As such, in this study, the perspectives of children with disabilities are drawn upon to challenge dominant negative perspectives that have been associated with disability within an Indian and global context and are also drawn upon to inform social transformation.

The critical disability lens also critiques the knowledge base on disability as predominantly embodying perspectives of people with disabilities from the minority world, that lacks perspectives from people from different cultures and geographical contexts, speaking different languages, and embodying different theories of participation and emancipation (Ghai, 2015; Meekosha & Shuttleworth, 2009). Furthermore, the voices of children with disabilities are identified as rarely addressed within disability scholarship, which is largely dominated by perspectives of adults with disabilities (Watson, 2012; Wickenden & Kembhavi-Tam, 2014). These diverse first-hand perspectives are situated as central in challenging the universality of disability theories by supporting the recognition of how socio-political, cultural, and historical forces merge with experiences of disability to inform a new disability perspective (Meekosha & Shuttleworth, 2009); a perspective that will situate the dialogue on disability as a global but diverse experience. Overall, through bringing the perspectives of children with disabilities to the fore front within the scope of my thesis project, I seek to respond to the call for deconstructing the existing body of disability scholarship with the amplification of voices often silenced from the majority world (Meekosha & Shuttleworth, 2009). The details of this analyses are presented in chapter six.
1.4.3 Research approach and methodological choice

Given that this dissertation is situated within the critical paradigm, informed by critical occupational science and critical disability perspectives, and embodying intents for collaboration with children with disabilities as means to address social transformation, a PAR approach was utilized. Specifically, this approach to research embodies commitments for equitable participation of community members as co-researchers in all phases of the research project as means for the end goal of addressing social transformation (Benjamin-Thomas, Corrado et al., 2018). A detailed description of this approach, also referred to as action research or transformative research, is addressed in chapter two (Benjamin-Thomas & Laliberte Rudman, 2018). Although various methods and methodologies can be used within PAR, participatory filmmaking, which falls within the broad umbrella of participatory digital methodologies, was used within the scope of this dissertation. Participatory digital methodologies involve the use of digital methods for research, and participatory filmmaking, also known as participatory videos, is the process where community members create videos as a means to document, explore, and critically engage with social issues (Gubrium & Harper, 2013; Mitchell, Milne & de Lange, 2012). More in-depth descriptions about participatory digital methodologies is provided in chapter three (Benjamin-Thomas, Laliberte Rudman et al., 2018) and more specifically on participatory filmmaking in chapter four (Benjamin-Thomas et al., under review).

1.5 Rationale and Purpose of this Dissertation

Globally, children with disabilities, especially those residing within the Global South have been identified as a collective experiencing occupational injustices by being denied opportunities for meaningful occupational participation (Parnes et al., 2009). Additionally, their first-hand perspectives are seldom heard within research (Wickenden & Kembhavi-Tam, 2014). In turn, there have been numerous calls for participatory and transformative research with children with disabilities (Gray & Winter, 2011; Stafford, 2017; Wickenden & Kembhavi-Tam, 2014).
However, there is a dearth of research within occupational science that embodies participatory approaches to collaborate with children with disabilities from the Global South as knowledge producers. Their first-hand perspectives are essential for challenging dominant assumptions related to disability and in mobilizing transformative agendas. Moreover, there have been calls within occupational science for epistemic reflexivity (Kinsella & Whiteford, 2009) as a means to interrogate what informs knowledge production within the discipline (Kinsella, 2012) and to expand its scholarship by legitimizing diverse perspectives on occupation that are outside of the dominant Western, middle-class, able-bodied, adult, female perspectives (Hammell, 2011; Hocking, 2012; Kantartzis & Molineux, 2012; Magalhães et al., 2019; Pollard et al., 2010). Specifically, perspectives from children with disabilities, especially from the majority world exist within the margins of the dominant occupational science scholarship. Methodological expansions within occupational science that incorporate participatory approaches have been articulated as one way forward for expanding core assumptions on occupation and occupational justice (Farias et al., 2019; Hartman, Mandich, Magalhães, & Orchard, 2011; Hocking, 2012; Huot & Laliberte Rudman, 2015). These expansions allow spaces for different ways of knowing and, in turn, for challenging ethnocentrism, power, and privilege within the discipline’s knowledge base (Hammell, 2011; Magalhães et al., 2019). Addressing these calls for diversifying the discipline’s scholarship through methodological expansions are considered essential for mobilizing transformative occupation-based research that seeks to address occupational injustices in global spaces.

The overall purpose of this dissertation is to develop and begin to mobilize an occupation-based transformative agenda by collaborating with children with disabilities from a rural village in Southern India. Specifically, the objectives entail working with children with disabilities as co-researchers in exploring their first-hand experiences about their lives pertaining to occupation; explicating the situated nature of their everyday experiences related to occupation and occupational justice; and working alongside them and community stakeholders in mobilizing change addressing situations of occupational injustices.
1.6 Plan of Presentation

This doctoral dissertation is presented in an integrated manuscript style, consisting of seven independent chapters that integrate conceptual and methodological reviews as well as make transparent, through reflexivity and theoretical analysis, the process and results of a participatory action research project. Although each chapter stands alone, they develop from one another and collaboratively address the larger purpose of this dissertation which is to enact an occupation-based transformative agenda as means to mobilize actions addressing occupational injustices. Overall, the first chapter serves as an introduction to this dissertation and the last chapter as the conclusion. All other chapters stand as published or submitted manuscripts or are in a format that is suitable to move forward to a journal for publication. A brief overview of the different chapters is provided in the section below. Table 2 provides an outline of manuscripts within this dissertation with their present publication status.

Chapter one serves as an introduction to the entire dissertation. It provides context to the other chapters by highlighting the rationale and purpose of this dissertation, disciplinary location of this work, the research context, and how disability is situated within that context. This is also where the research approach, methodological choice, and theoretical lenses used within this dissertation are introduced. In this chapter, I also make transparent my paradigmatic position, and my relationship to the research context and topic of focus.

Chapter two introduces the first of five integrated manuscripts. This manuscript presents a critical interpretive synthesis of literature that explored how the key tenets of the occupational justice framework were embodied within occupational justice research. The findings indicated that research employing the occupational justice framework was predominantly used to identify occupational injustices, and less frequently included mobilizing actions towards addressing situations of injustices. In turn, the findings echoed the call for more critically-oriented transformative work within occupational science.

Chapter three emerged out of my candidacy exam which sought to address methodological expansions within the discipline of occupational science as a means for
mobilizing transformative research agendas. This methodological review explored the utility of three emerging participatory digital methodologies (i.e., digital storytelling, participatory videos/participatory filmmaking, participatory geographic information system) as a means to support transformative research within occupational science, with specific application among children and youth. Within this paper, I was able to critically analyze how these emerging methodologies were utilized across disciplines within transformative research with children and youth in ways that also addressed occupation. This paper explored and discussed strengths and challenges for each methodology with regard to how participation of children and youth was demonstrated; how transformation was addressed at personal and societal levels; and potential for application within transformative research among children and youth within occupational science.

Chapter four and five, the third and fourth integrated manuscripts, specifically address the call for methodological expansions within occupational science as a means for enacting transformative research. Specifically, chapter four highlights participatory filmmaking as a research methodology committed to promoting inclusivity that has the potential to support collaboration with children with disabilities. This chapter also makes transparent the participatory filmmaking research process used in this dissertation, highlighting the different phases of this participatory action research project, activities carried out within each phase, as well as strategies used to address pragmatic challenges as means to promote collaboration of children with disabilities as co-researchers. This chapter goes side by side with chapter five that specifically addresses the ethical tensions faced within the participatory filmmaking process and makes transparent the process of critical reflexivity used within this process to better enact ethical research practices.

Chapter six presents the results from this project that are explicated through participatory thematic analysis and theoretical analysis. First, the four themes resulting from participatory thematic analysis carried out in collaboration with children with disabilities are detailed; namely, navigating desired occupations within existing boundaries; experiences of occupational injustices; inter-related social issues of violence and substance abuse; and environmental concerns related to garbage and deforestation. Second, themes related to the situated nature of occupational injustice and disability that
evolved from a critical theoretical analysis informed by a critical occupational science perspective and critical disability perspectives are presented. Finally, a section addressing how transformation has, and is planned to be, enacted through this research project is presented.

Chapter seven, the concluding chapter, presents a synthesis of key insights gained from this work in relation to the purpose of this dissertation. Based on the new knowledge gathered from this doctoral work, methodological and theoretical implications for occupational science, as well as implications for educational policy development in rural India, are discussed. Ways forward for future research directions addressing occupation-based transformative research and research addressing disability within occupational science are also presented. Additionally, this chapter highlights quality considerations that were embodied within this work, and ends with my personal reflections highlighting strengths, boundaries and new learnings through this process.

Table 2. Manuscript Publication Status

<table>
<thead>
<tr>
<th>Chapter #</th>
<th>Chapter Title</th>
<th>Journal</th>
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<tbody>
<tr>
<td>1</td>
<td>Introduction</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>2</td>
<td>A critical interpretive synthesis: Use of the occupational justice framework in research</td>
<td>Australian Occupational Therapy Journal</td>
<td>Published</td>
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<tr>
<td>3</td>
<td>Participatory digital methodologies: Potential of three approaches for advancing transformative occupation-based research with children and youth</td>
<td>Journal of Occupational Science</td>
<td>Published</td>
</tr>
<tr>
<td>4</td>
<td>A participatory filmmaking process with children with disabilities in rural India: Working towards inclusive research</td>
<td>Methodological Innovations</td>
<td>Submitted May 2019</td>
</tr>
<tr>
<td>5</td>
<td>Navigating ethical tensions through critical reflexivity: A participatory filmmaking project</td>
<td></td>
<td>Pending Submission</td>
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<tr>
<td>6</td>
<td>Issues of occupational justice prioritized and explicated by children with disabilities from rural India</td>
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<td>7</td>
<td>Discussion</td>
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1.7 Summary

My dissertation work is a response to increasing calls for a critical, transformative, inclusive and international occupational science that seeks to enact transformative occupation-based agendas addressing occupational injustices at local scales in diverse global spaces (Hocking & Whiteford, 2012; Laliberte Rudman, 2014; Laliberte Rudman et al., 2008). Specifically, this work explores and addresses issues related to occupational injustices experienced by children with disabilities from a rural village in the Global South. First-hand perspectives of children with disabilities have been situated as central in mobilizing transformation addressing issues affecting them (UNICEF, 2007). However, their perspectives, especially children with disabilities from the Global South, are rarely included in research (Kembhavi & Wirz, 2009; Wickenden & Kembhavi-Tam, 2014).

A PAR project with children with disabilities from a rural village in Southern India was carried out as a thesis project within this dissertation. To facilitate inclusion of children with disabilities as co-researchers within this project, participatory filmmaking (Gubrium & Harper, 2013; Mitchell, Milne & de Lange, 2012) was used as a research methodology. This methodology created a space for children with disabilities to share their first-hand perspectives on occupation and issues related to justice that they deemed as relevant. The utilization of this emerging methodology addresses, in part, the call for methodological expansions within occupational science as a means to facilitate diverse and global perspectives on occupation and occupational justice that remain in the margins of the discipline’s knowledge base. These first-hand perspectives of children with disabilities from rural South India are drawn upon to further explicate understandings of the situated nature of disability, occupation, and occupational injustices. In turn, these explications are positioned to inform the mobilization of socially transformative agendas addressing occupational injustices experienced by children with disabilities as well as their extended community.
1.8 References


Hocking, (2012). Occupations through the looking glass: Reflecting on occupational scientists’ ontological assumptions. In G. E. Whiteford & C. Hocking (Eds.),


Chapter 2 3

2  A Critical Interpretive Synthesis: Use of the Occupational Justice Framework in Research

Within occupational therapy and science, the concept of occupational justice has contributed to a heightened awareness of injustices faced by many individuals and communities in the form of being denied opportunities to participate in occupations (Durocher, Gibson & Rappolt, 2014). The occupational justice framework was established with an agenda to guide work, inclusive of research and practice, that both identifies and also addresses injustices pertaining to occupation (Durocher, Gibson et al., 2014). This framework embodies a motive to ‘spur action’ towards a shared utopian vision of an occupationally just world “that would be governed in a way that enables individuals to flourish by doing what they decide is most meaningful and useful to themselves and to their families, communities, and nations” (Stadnyk, Townsend & Wilcock, 2010, p. 330).

Enhancing the social relevance of occupation-focused research and moving occupational therapy practice into social realms have been identified as key directions for development (Malfitano, Lopes, Magalhães & Townsend, 2014; Molineux & Whiteford, 2011). Commensurate with such directions, the occupational justice framework could be drawn upon to embrace a knowledge to action continuum so as to further build a socially responsible science committed to social transformation (Laliberte Rudman, 2014). In particular, incorporating action research approaches within studies addressing occupational injustices could enable scholars to work collaboratively so as to implement social change (Altheide & Johnson, 2011; Richardson & MacRae, 2011).

The extent to which the occupational justice framework has been used in research in ways that embrace action is the focus of this paper. More specifically, key guiding questions include: ‘how has the occupational justice framework been used within occupation-focused research? To what extent has such research embraced action research as a means to enact social change to address occupational injustices?

Following a brief outline of the historical development of the occupational justice framework, we provide the working definition of ‘occupational justice’ that guided this critical interpretive synthesis (CIS). We then overview what action research is, and provide our working definition. After outlining our methodology and methods, we present the results of this CIS to map out how occupational justice has been integrated into research. Although acknowledging that generating knowledge is an important research contribution and that raising critical awareness of occupational injustices is one form of action that can promote social change, we point to the relative absence of action research or other methodologies that more fully encompass social change within their objectives. We conclude by raising questions regarding dominant trends in the research reviewed, aiming to facilitate dialogue regarding ways to move forward in the application of the occupational justice framework for action research and social change.

2.1 The Occupational Justice Framework

The occupational justice framework was proposed by Townsend and Wilcock in the late 1990s, based on the fundamental premises that participation in meaningful occupations is an individual right and being prevented from such participation is a form of injustice (Townsend & Wilcock, 2004; Wilcock & Townsend, 2000). While acknowledging ongoing dialogue regarding the relationship between ‘occupational justice’ and ‘social justice’ (Durocher, Gibson, et al., 2014) and critiques regarding embeddedness in a Western conceptualization of justice (Durocher, Rappolt & Gibson, 2014), it can be argued that occupational justice is unique in its explicit focus on issues of justice related to occupation (Stadnyk et al., 2010). As well, the occupational justice framework embodies certain underlying values and assumptions, specifically: all individuals are occupational beings (Stadnyk et al., 2010), participation in meaningful occupation leads to positive health, well-being, and social inclusion (Townsend & Wilcock, 2004), and
participation in occupation is influenced by, and occupational injustices are shaped through, contextual forces (Townsend, 2015).

For the purposes of this paper, occupational justice was conceptualized as a framework that emphasizes the need for individuals and communities to participate in meaningful occupations as means to maintain and enhance health and well-being (Stadnyk et al., 2010). When participation in occupations has been “barred, confined, restricted, segregated, prohibited, underdeveloped, disrupted, alienated, marginalized, exploited, excluded or otherwise restricted” (Townsend & Wilcock, 2004, p. 77) it is seen as an occupational injustice, which can present as occupational deprivation, occupational marginalization, occupational alienation, occupational imbalance, or occupational apartheid (Durocher, Gibson et al., 2014). The occupational justice framework embodies a moral commitment to address injustices and promote equitable opportunities for meaningful occupations (Townsend & Wilcock, 2004; Wilcock & Townsend, 2000). Given this commitment, we argue for the utility of action research as means to not only identify occupational injustices, but also inform social transformation aimed at ameliorating such injustices.

### 2.2 What is Action Research?

As defined by Greenwood and Levin (2007) “action research refers to the conjunction of three elements: action, research, and participation. Unless all three elements are present, the process may be useful but it is not action research” (p. 5). Action research, by definition, embraces but extends beyond understanding and raising awareness of a social problem, to taking steps towards social transformation (Fine & Barreras, 2001; Meyer, 2000; Schwandt, 2001). Freire’s concept of praxis: “reflection and action upon the world in order to transform it” (as cited in Fillmore, Dell & Kilty, 2014, p. 57) is a key philosophical basis for ‘action research’, particularly participatory approaches. More broadly, action research is underpinned by critical epistemological frameworks, leading to work that seeks to: challenge the status quo; conceptualize injustices as a consequence of unequal power structures; and, change systems that perpetuate injustices for marginalized groups (Crotty, 1998; Ponterotto, 2005). Furthermore, a key component of action research involves ‘participation’, where researchers and societal members
collaborate in all phases of the research-action process (Altheide & Johnson, 2011; Meyer, 2000). Therefore, critical participatory action research seeks to “change practices, people’s understandings of their practices, and the conditions under which they practice” (Kemmis, McTaggart & Nixon, 2014, p. 59).

Given the commitment to social change, researchers who are involved in critically-located action research challenge the research versus practice, or knowledge versus action, dichotomy. Action is broadly conceptualized and measured in numerous ways, from raising critical consciousness within communities (Freire, 1970) to changing social structures (Meyer, 2000). Furthermore, action is considered as both a process of research, where participants are transformed, and a product of research (Johnson & Parry, 2015a). Thereby, drawing upon these key features of action research, we consider the extent to which principles and practices of action research have been implemented in research that has used an occupational justice framework.

2.3 Methods & Methodology

This paper presents a critical interpretive synthesis (CIS: Dixon-Woods et al., 2006) of published research that employed an occupational justice framework. A CIS moves beyond summarizing research content or critiquing methods to question the taken-for-granted assumptions and dominant tendencies that research embodies, seeking to open up dialogue about other research possibilities (Barnett-Page & Thomas, 2009; Flemming, 2010). This synthesis approach incorporates an iterative process of formulating research questions based on on-going search results (Dixon-Woods et al., 2006). Our initial intent was to focus on articles and book chapters that linked occupational justice and action research explicitly, however, an initial search revealed only 4 sources. Thus, the focus of the search was expanded to include articles and book chapters that explicitly articulated using the occupational justice framework to inform research. In turn, the foci for this critical interpretive synthesis were to: (1) explicate how the concept of occupational justice has been used within research, and (2) critically examine the aims and implications of such research, relating this to the continuum of knowledge generation to action.
In concert with quality criteria for critically-informed research (Whittemore, Chase & Mandle, 2001) we situate this CIS, which was led by the first author in the context of a graduate course for which the second author was the facilitator, by explicating the authors’ motivations for writing this paper and for moving occupational justice scholarship to action:

First author: I share some of my personal reflections on how I was a witness to many situations of occupational injustices during my time in practice as an occupational therapist. These reflections help me contextualize, and articulate, why I am passionate towards addressing issues of occupational injustices around the globe. As Johnson and Parry (2015a) state, “most of us come to a social justice paradigm because we have experienced injustice in our own lives and want to do something about it” (p. 11). Reflecting on my past experiences as an occupational therapist working among rural communities in India, I was sensitized to the occupational needs of children with disabilities who were often denied opportunities to participate in meaningful occupations. Specifically, I have been a witness to sights where children with disabilities were tied to objects inside their houses as a safety and precautionary measure. I have also heard from parents of children with disabilities, and from children themselves, on how schools often denied admissions for children with disabilities due to their disability status. These discriminations often seemed based on the socially and politically constructed concept of ‘ableism’ (Goodley, 2014). These experiences then positioned my assumptions regarding the construct of ‘occupation’, to be considered as right for all individuals irrespective of their age, class, race or abilities. I was also sensitized to the need for occupational therapists and other practitioners to advocate within, and fight against, the socio-political realms that seemed to be the forces perpetuating occupational injustices. Specifically, the systems that were indeed geared to promote participation of children with disabilities were implicitly marginalizing them as the ‘not normal’ children. There were many children with sound intellectual abilities, like children with muscular dystrophy, who were asked to leave school once they were wheelchair dependent, due to them attaining a disability status coupled with environmental barriers like
the inaccessible school environment. These experiences stirred a passion for
justice that I wanted to address, and therefore, the occupational justice framework
is a tool that I have come to see as something occupational scientists, occupational
therapists, and other social scientists, could use to identify and address issues of
occupational injustices faced by individuals and communities across the globe.

Second author: Within my research career, I first focused on doing constructivist
forms of qualitative inquiry aimed at understanding diverse perspectives,
experiences, and realities, as a means to expand conceptualizations of occupation
and diversify occupational therapy practices. Within this work, I became
increasingly concerned with the ways in which situations of inequity, related to
ability status, age, gender, and other social locations, were often framed as either
the ‘way the world is’ or as resulting from individual deficits. Beginning in my
PhD studies, I have increasingly shifted towards critical qualitative forms of
inquiry, seeking to question and analyze taken-for-granted structures, systems,
and discourses that individualize socio-politically produced issues and shape
occupational inequities and injustices. Although I firmly believe that such
questioning and the raising of social awareness of the root causes of inequities
and injustices is needed to spark social change, I believe that we have a moral
responsibility as occupational scientists and therapists to engage with
communities that experience such inequities and injustices to address the root
causes and work to transform the ‘status quo’. This has led me to an exploration
of transformative scholarship, and to on-going critical reflexivity regarding the
dichotomy often drawn between ‘science’ and ‘action’ within the institutions I am
embedded in. This paper represents one attempt to question this often taken-for-
granted division, and to push critical scholarship in occupational therapy and
science to diverse forms of action.

Both databases and books were searched to build a comprehensive sample of relevant
texts. Three databases (CINAHL, Scopus, PubMed) were systematically searched using
key words and subject headings (i.e., occupational justice, research, action-research) in
various combinations. A hand search of references from identified articles was also
completed. The second author identified potential books that incorporated the occupational justice framework in research. The books were screened to identify chapters that fit with the inclusion criteria. Inclusion criteria were: 1) written in English; 2) used the occupational justice framework, which was made explicit in the title, abstract or keywords; 3) explicitly situated the work as a research study; 4) published between January, 2000 and May, 2016. Exclusion criteria included the use of the occupational justice framework for a literature review, reflection on practical scenarios, workshop discussions, or describing occupational therapy programs. The search resulted in a sample of 20 articles and 3 book chapters (See Table 3 for listing of included sources).

Analysis within CIS focuses on understanding how a particular construct is conceptualized and studied. In this CIS, we focused on 1) how the concept of occupational justice was used within research, and 2) how the research aims and implications were related to the continuum of knowledge generation to action. The initial analysis involved an iterative process of reading articles and writing reflexive comments with regard to how research was conducted, how action was demonstrated, and how the occupational justice framework was conceptualized. Themes across the texts were constructed by the first author, with themes reflecting recurring ways of studying and conceptualizing occupational justice as well as recurring absences or silences. Written iterations of evolving themes, along with supporting data, were reviewed by and discussed with the second author, informing further analysis, reflexivity and refinement of themes. Thus, consistent with the approach described by Dixon-Woods and colleagues (2006), the analysis, and subsequent critical interpretation, was continuously developed based on reflexivity and dialogue.

Table 3. List of Articles/Book Chapters Included in the Critical Interpretive Synthesis

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Jakobsen, K</td>
<td>2004</td>
<td>If work doesn't work: How to enable occupational justice.</td>
</tr>
<tr>
<td>2. Galvaan, R</td>
<td>2005</td>
<td>Domestic workers’ narratives: Transforming occupational therapy practice</td>
</tr>
<tr>
<td>3. Häggblom-Kronlöf, G., &amp; Sonn, U</td>
<td>2005</td>
<td>Interests that occupy 86-year-old persons living at home: Associations with functional ability, self-rated health and sociodemographic characteristics</td>
</tr>
<tr>
<td>No.</td>
<td>Authors</td>
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<tr>
<td>4.</td>
<td>VanLeit, B., Starrett, R., &amp; Crowe, T. K</td>
<td>2006</td>
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<tr>
<td>10.</td>
<td>van Niekerk, L</td>
<td>2009</td>
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<tr>
<td>15.</td>
<td>Beagan, B. L., De Souza, L., Godbout, C., Hamilton, L., MacLeod, J., Paynter, E., &amp; Tobin, A</td>
<td>2012</td>
</tr>
<tr>
<td>16.</td>
<td>Guptill, C</td>
<td>2012</td>
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<td>17.</td>
<td>Mirza, M</td>
<td>2012</td>
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<td>19.</td>
<td>O'Sullivan, G., &amp; Hocking, C</td>
<td>2013</td>
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2.4 Occupational Justice Research: Foci, Emphases, and Absences

The findings for this CIS are presented in themes that reflect dominant ways occupational justice was enacted in research. The first theme identifies that despite some variation, the occupational justice framework was predominantly used as a lens to interpret research findings. The second theme addresses a dominant tendency to individualize situations of occupational justice, while the third theme highlights absences and silences.

2.4.1 Approaches to incorporating occupational justice into research

Within the research reviewed, the occupational justice framework was most commonly incorporated as a lens to interpret findings (Aldrich & Callanan, 2011; Beagan et al., 2012; Galvaan, 2005; Guptill, 2012; Häggblom-Kronlöf & Sonn, 2005; Holthe, Thorsen & Josephsson, 2007; Mirza, 2012; Pettersson et al., 2014; VanLeit, Starrett & Crowe, 2006; van Niekerk, 2009). For example, Aldrich and Callanan (2011), reflecting on an ethnographic study with discouraged workers from a rural community in North Carolina, integrated occupational injustice to interpret a theme addressing disappearance (p. 161). Mirza (2012) explored how resettlement policies influenced occupational participation of refugees with disabilities within the United States, articulating: “the findings suggest that disabled refugees could be at a risk of occupational deprivation after resettlement” (p. S12). As another example, van Niekerk (2009), who explored the work-lives of people with psychiatric disabilities in South Africa, highlighted that “their narratives revealed the role of work in promotion of occupational justice and in identity construction” (p. 456).

Occupational justice was also used as an interpretive lens within secondary analysis of data collected for different research purposes (Arthanat, Simmons & Favreau, 2012; Beagan et al., 2012; Czymoniewicz-Klippel, 2011; Du Toit, Böning & Van Der Merwe, 2014; Paul-Ward, 2009; Sakellariou & Algado, 2006). For example, Arthanat and colleagues (2012) conducted a secondary analysis of interview data to “elucidate themes of occupational justice and injustice” (p. 311) from a larger study of measurement indicators of assistive technology usability based on consumer experiences. Similarly,
Beagan and colleagues (2012) used an occupational justice lens on a subsample from a qualitative study on “health and well-being of LGBTQ women” (p. 229), stating that, “this occupational analysis of stories of 5 transgendered participants was not the initial focus of the research. Rather, the rich occupational data contained in broader interviews demanded closer examination” (p. 229).

Several authors employed occupational justice to articulate implications of research findings for occupational therapy practice, emphasizing the responsibility of occupational therapists to address injustices (Arthanat, et al., 2012; Blakeney & Marshall, 2009; Du Toit, Böning & Van Der Merwe, 2014; Gallagher, Pettigrew & Muldoon, 2015; Galvaan, 2005; Holthe et al., 2007; Mirza, 2012; O’Sullivan & Hocking, 2013; Paul-Ward, 2009; Pettersson et al., 2014; Sakellariou & Algado, 2006; VanLeit et al., 2006). For example, Galvaan (2005), after identifying the presence of occupational restriction amongst live-in domestic workers in South Africa, suggested that, “occupational therapists encountering domestic workers in clinical practice are ethically obliged to address the occupational risk factors and injustices that could lead to the development of impairments and disabilities” (p. 437). Pettersson and colleagues (2014), building from the results of a study examining the perspectives of powered mobility device (PMD) users, highlighted that: “occupational therapists are well qualified to contribute to an enhanced understanding of PMD users’ challenges in person-environment-occupation transactions in the home and society. To enable optimal PMD use and to foster occupational justice the service delivery process must be improved” (p. 445). More specifically addressing contextual features, Gallagher and colleagues (2015), who explored the ‘occupational choice of youth in disadvantaged communities’, concluded that “occupational therapists need to create practice opportunities within political and institutional environments to address disabling structures that constrain occupational choice as a matter of occupational justice” (p. 628).

Much less frequently, researchers used the occupational justice framework to guide their research question or study purpose (Czymoniewicz-Klippel, 2011; Gallagher et al., 2015; Galvaan et al., 2015; Galvin, Wilding & Whiteford, 2011; Jakobsen, 2004; Kramer-Roy, 2011; Lo Bartolo & Sheahan, 2009; Paul-Ward, 2009; Sakellariou & Algado, 2006). For
example, Paul-Ward (2009), in research aimed at incorporating adolescents’ perspectives on foster care, articulates the purpose of her research as, “to discuss the value of incorporating a social justice and occupational justice perspective into the research and practice realms of occupational therapy” (p. 82). Czymoniewicz-Klippel (2011) applied the occupational justice framework to understand the childhoods of Cambodian children, aiming to illustrate, “the value of employing an occupational justice framework in childhood research” (p. 378). Additionally, Lo Bartolo and Sheahan (2009) used the occupational justice framework within a critical discourse analysis aimed “to explore the occupational justice issues arising from the proposed industrial relations reforms” (p. 407) within the Australian labor market.

Only four articles explicitly used the occupational justice framework for action research (Blakeney & Marshall, 2009; Galvin et al., 2011; Kramer-Roy, 2011; O'Sullivan & Hocking, 2013). Given the initial intent of this CIS, these studies are described in further detail attending to how occupational justice and action research were integrated. O'Sullivan and Hocking (2013) used an action research approach “to explore the daily activities of people who live with dementia in the community” (p. 168), employing occupational justice to interpret their findings. Based on diverse qualitative data collected with clients with mild to moderate dementia and their primary caregivers, the authors found that community-dwelling individuals with dementia had reduced opportunities for meaningful occupations, and thereby faced occupational injustices. With respect to how action research was employed, these authors focused more on the commitment to enacting change and less on participation: “action research is a term that refers to a range of research activities that may be better described as applied research because they do not always require participation. It is, more or less, a systematic research process that aims to change three things: practices, understandings, and the conditions of practice” (p. 170). With respect to action, they focused on opening “communicative spaces to explore the ‘way things are’ and point to a course of action” (p. 170).

Galvin and colleagues (2011) used a collaborative action research methodology to investigate occupational therapists’ understanding of human rights theory and the occupational justice framework, aiming to promote enhanced attention to rights and
justice within practice. Action, and participation, within this study embodied the use of
dialogue to facilitate critical reflection so as to enable co-researchers “to simultaneously
reflect upon and act upon their practice” (p. 380). The authors indicated this form of
action was displayed: “a way that the participants were able to better recognize the
human rights needs of their clients was to begin a dialogue with each other and with a
researcher who encouraged them to think critically about their practice” (p. 383).

Kramer-Roy (2011) used a participatory action research approach to engage Pakistani
families of children with disabilities residing in the UK. She aimed to identify and
address support needs from an occupational justice perspective, and explored how
cultural and familial expectations impacted the occupational balance of family members.
Consistent with participatory principles, Kramer-Roy articulates that “the process of
facilitating the participants to engage in the research was as important as the content” (p.
387). Three different action groups, based on gender and age, from six families of
children with disabilities were formed. Each group identified issues of relevance, and
engaged with the researchers in planning, implementing action, and reflecting on actions.
For example, the action undertaken by the women’s group was “to design and distribute
leaflets inviting other Pakistani women to join their support group” (p. 388), while the
men’s group addressed issues related to the social forces contributing to disability. “They
decided to consult Islamic scholars to find out what the Qur’an and other early Islamic
scriptures actually say about disability, so they could use that knowledge in challenging
community attitudes” (p. 388).

Blakeney and Marshall (2009) also used a participatory action research approach, where
the research question was generated by a committee of individuals living in a particular
county who were subsequently involved in the entire research process. This three-phased
research project, which incorporated the disciplines of geography, sociology and
occupational therapy, examined how water quality influenced occupational participation
of individuals living in Letcher County, Kentucky. The first two phases involved
mapping the watershed in the county, and surveying health county professionals.
Subsequent results were presented to the county members to raise consciousness about
the problem, which in turn, informed the third phase that focused on listening to
individuals’ occupational experiences to identify occupational injustices. The final project report was used to obtain $24 million in grant monies for water improvement projects within that county.

2.4.2 The tendency to individualize occupational justice

Individualizing of issues refers to framing a problem at the individual level, “explored only in relation to what happens to the people who experience it, rather than forces beyond the individual that bring it about” (Hocking, 2012, p. 59). Within the articles reviewed, most authors focused on exploring individual experiences of occupational injustices (Beagan et al., 2012; Czymoniewicz-Klippel, 2011; Du Toit et al., 2014; Gallagher, et al., 2015; Galvaan et al., 2015; Guptill, 2012; Holthe et al., 2007; Jakobsen, 2004; O'Sullivan & Hocking, 2013; Pettersson et al., 2014; Sakellariou & Algado, 2006; VanLeit, Starrett & Crowe, 2006). For example, Du Toit and colleagues (2014) explored occupational engagement of SeSotho-speaking elders living in residential care, identifying elders’ experiences of loneliness, helplessness, and boredom. Sakellariou and Algado (2006) used an occupational justice lens in a broader study “designed with the aim of gaining understanding of the lived experiences of men with a spinal cord injury regarding their sexuality” (p. 71). Within such studies, exploring individual experiences was framed as a means to raise awareness of occupational injustices within particular collectives.

Although raising awareness can be a critical first step to addressing occupational injustices (Townsend & Whiteford, 2005), further understanding social mechanisms of injustice is required to inform social transformation. However, a focus on individual experiences does not necessarily equate with individualizing, as the experiences of individuals were sometimes analyzed to highlight the socio-political production of injustices. For example, Galvaan and colleagues (2015) explored the experiences of employers of live-in domestic workers to gain a better perspective on how they, on exercising their occupational rights from a position of privilege, create conditions of occupational injustices for domestic workers. Overall, about half of the articles attempted, to varying extents, to elucidate socio-political forces shaping and perpetuating injustices (Beagan et al., 2012; Czymoniewicz-Klippel, 2011; Gallagher et al., 2015;
O’Sullivan and Hocking (2013) pointed to systemic barriers that contribute to occupational injustices for community-dwelling individuals with dementia, such as service providers’ limited knowledge: “the idea that little can be done to help people living with dementia is indicative of inequities that have arisen because service providers lack understanding of the support required to enable them to live in the community” (p. 173). Paul-Ward (2009), who used a social and occupational justice lens to analyze barriers faced by adolescents to successful transition out of the foster care system, also pointed to systemic issues “it becomes clear that many of the challenges that these youth face result from the bureaucratic system in which they are placed” (p. 86). Therefore, although there appears to be a dominant explicit focus on individual experiences of injustices, there also appears to be growing attention to social or political forces even when the focus of study is on individual experiences.

2.4.3 Absences and silences in the occupational justice research

Within CIS there is attention to not only what is in a body of literature, but also what seems absent given certain implicit boundaries. For example, occupational justice research was found to be predominantly carried out in developed countries like Australia (Galvin et al., 2011; Lo Bartolo & Sheahan, 2009), United States of America (Aldrich & Callanan, 2011; Arthanat et al., 2012; Blakeney & Marshall, 2009; Mirza, 2012; Paul-Ward, 2009; VanLeit et al., 2006), Canada (Beagan et al., 2012; Guptill, 2012), Sweden (Häggblom-Kronlöf & Sonn, 2005; Pettersson et al., 2014), Norway (Holthe et al., 2007; Jakobsen, 2004), New Zealand (O’Sullivan & Hocking, 2013), Greece (Sakellariou & Algado, 2006), Ireland (Gallagher et al., 2015), and the United Kingdom (Kramer-Roy, 2011), with only a handful of research from other regions of the world like Cambodia (Czyimoniewicz-Klippel, 2011) and South Africa (Du Toit et al., 2014; Galvaan, 2005; Galvaan et al., 2015; van Niekerk, 2009).

It was also evident that occupational injustices were predominantly identified as a ‘lack of opportunity’ to participate in meaningful occupations, with limited research on how ‘forced participation’ (Hocking & Whiteford, 2012) in occupations, such as child labour
practices, street begging, forced prostitution, contributes to occupational injustices. This void may highlight a predominant Western conceptualization of occupational injustice that prioritizes individual choice and problematizes reduced opportunities for control (Laliberte Rudman & Dennhardt, 2008). This emphasize may obscure, or neglect, situations in which large proportions of individuals are forced into occupations that are not meaningful to them, rather than have reduced choice.

2.5 Paving the Way Forward: The Occupational Justice framework for Action Research

Montague’s maxim (2001) points out that, “justice consists of giving everyone his due” (as cited in Sakellariou & Algado, 2006, p. 74). For the authors of this paper, based on their on-going critical reflexivity regarding their clinical and research experiences, key critical questions to reflect on are: when the occupational justice framework is used for research, are we giving back to people identified as experiencing injustices? Are we attending to our moral responsibilities as scientists and therapists? If research on occupational justice does not embody steps to take after identifying injustices, then should we claim to be using a ‘justice’ oriented framework? We contend that although identifying and raising awareness of injustices is an important step (Townsend & Whiteford, 2005), it is important to further consider how to extend beyond such identification. As Denzin and Giardina (2009) articulate, “we are no longer called to just interpret the world… today, we are called to change the world and to change it in ways that resist injustice while celebrating freedom and full, inclusive, participatory democracy” (p. 13). Based on the first author’s experience, this call to ‘change the world’ is imperative given that numerous individuals and communities across the globe are daily being subject to oppressive forces that implicitly and explicitly create situations of occupational injustices, and as occupational therapists and scientists we are called to collaborate with these communities to challenge the status quo and affect social change (Townsend & Wilcock, 2004). For the second author, Denzin and Giardina’s call to highlight the moral and political responsibilities of researchers is particularly timely given the increasing focus on occupation as a human right and a political phenomenon (Farias, Laliberte Rudman & Magalhães, 2016; Hocking & Whiteford, 2012), as well as
mounting concerns regarding the ways in which neoliberalism obscures the socio-
political production of various forms of inequities and injustices and perpetuates
marginalization of particular societal groups (Gane & Back, 2012).

Critical social scientists who are interested in using research for social justice have
pointed to the necessity of breaking down the dichotomy of researchers as scientists, and
practitioners for action (Fine & Barreras, 2001; Laliberte Rudman, 2014). We contend
that further breaking down this dichotomy is required if occupational therapist and
scientists want to move forward in the goal of shaping a more occupationally just world.
To expand beyond providing implications for practice that stem from research findings, it
is important to explore the possibilities of adopting a critical paradigmatic position that
does not separate the researcher from the researched, and that provides theoretical and
methodological means to challenge power relations and other perpetuating forces of
injustice (Denzin & Giardina, 2009). Further embracing a critical lens towards
understanding occupational injustices would shift research from a dominant position of
describing experiences as occupational injustices towards addressing the root causes of
such injustices and actions to address them (Angell, 2014). This lens, in turn, might help
further drive changes at social and political levels rather than solely at the individual
level. This critical stance would help challenge and expand how the occupational justice
framework has been applied within research to date.

Trentham and Cockburn (2005) argue that participatory action research (PAR), “is an
approach to knowledge development that is consistent with the values of occupational
therapy and principles of occupational justice” (p. 440). Furthermore, Townsend and
Whiteford (2005) propose occupational justice as a participatory framework, and
emphasize “participation in negotiating a justice framework” (p. 123). A PAR approach
embodies the pluralistic intents of enhancing understanding, building theory, and
instigating action, emphasizing the researcher collaborating with participants, as co-
researchers, in identifying problems, analyzing data, disseminating findings, and deciding
and enacting action plans (Grimwood, 2015). Moreover, PAR has the potential to address
inequities in power in its process as it is “particularly beneficial for marginalized
populations whose voices are seldom represented in the scholarship” (Johnson & Parry,
Linking with an emphasis on critical scholarship, “PAR practitioners embrace a critical social science perspective in their acknowledgement that existing social structures are unjust, benefiting privileged groups over marginalized groups, and are therefore in need of change” (Trentham & Cockburn, 2005, p. 442). The potential contribution of a PAR approach is supported by work in other disciplines addressing racism, ableism, sexism, heterosexism, and imperialism (Grimwood, 2015). For example, Walker and Early (2010) used Photovoice and PAR to examine barriers that non-governmental organizations and caregivers faced when providing care for orphaned and abandoned children in Sierra Leone. The community members were an integral part of the research team, involved in identifying problems as well as proposing immediate action plans for the non-governmental organization and long-term action plans for the community and government. The proposed actions, such as, educating community members about healthy environments and increasing the number of orphanages in Sierra Leone, were subsequently initiated by the organization. Therefore, PAR, amongst other action-oriented methodologies, is a tool that researchers using the occupational justice framework need to embrace so as to promote action towards addressing global issues of inequities and injustices.

It is acknowledged that occupational therapists proposed the occupational justice framework as a social vision and embedded value of occupational therapy (Townsend & Wilcock, 2004), but we would argue that occupational justice is a vision shared by other disciplines and thus requires interdisciplinary collaboration (Ikiugu & Pollard, 2015). Bailliard (2016) reiterates this point by stating, “transdisciplinary collaborations provide greater granularity to the multiple factors contributing to situations of injustice, potentially expanding the repertoire of conceived intervention possibilities, and minimizing the risk of ineffective or misguided interventions” (p. 9). Moreover, by not reaching out to and engaging with other disciplines it is unlikely that complex issues, or ‘wicked problems’ underlying occupational justices can be effectively addressed (Wicks & Jamieson, 2014). Blakeney and Marshall (2009) illustrate the potential benefits that can arise from interdisciplinary collaboration while adding in an occupational lens. Their research project addressing water quality, which resulted in increased governmental
support, involved collaborations with geographers, sociologists and community members, as well as contributing an occupational justice lens.

Wilcock and Townsend (2009) define occupational justice as a justice of difference, “because people have different natures, needs, and capacities … within the social and ethical standards of a community” (p. 193). This notion of difference can contribute to a broadened conceptualization of occupational justice, expanding the lens to more fully addressing, for example, occupational injustices that result from ‘forced participation’ (Hocking & Whiteford, 2012). By embodying this agenda, it would create spaces for the inclusion of marginalized voices, and stories, from various cultural and geographic backgrounds, highlighting diverse realities on issues pertaining to occupational injustices.

2.6 Conclusion

Molineux and Whiteford (2011) articulate, that within the discipline of occupational science, “research has been compromised in its usefulness by a lack of regard for application in real-world contexts” (p. 247). The occupational justice framework was proposed with the intent that scholars advocate about and address occupational injustices prevalent across the globe. Ikiugu and Pollard (2015) articulate, “some of the pressing issues of concern in current times include: a rapidly growing population, environmental degradation...and increasing income inequalities” (p. 160). These global issues reflect in the form of occupational injustices, meaning that the occupational justice framework can provide an occupational lens for examining and acting on local to global issues (Stadnyk et al., 2010).

From this critical interpretive synthesis, it appears that this framework has thus far been predominantly used within the context of research to identify occupational injustices in various communities and settings, with a dearth of literature on the uptake of this framework for action research. Most articles implicitly sustained a dichotomous view of science and action, as authors commonly provided occupational therapy practice implications at the end of their research studies maintaining a line between knowledge generation and action. For the occupational justice framework to be more fully used, scholars need incorporate approaches, such as PAR, that embody inclusion and justice.
Moreover, to effectively encompass the knowledge to action continuum in occupational justice research, it is vital that occupation-based scholars, enacting research to practice, practice epistemic reflexivity (Kinsella & Whiteford, 2009) to ensure a sensitivity and openness to multiple ways of understanding occupational justice at local to global scales; adopt a critical stance that addresses the socio-political production of injustices; and engage across disciplinary fields to capture the various factors that shape and perpetuate injustices. Preparing occupation-based scholars for the on-going practice of epistemic reflexivity also demands integration of a critical approach to occupational therapy education. Such an approach would facilitate development of critical awareness about how practices are embedded within power relations and could be a site to perpetuate or transform experiences of occupational injustices (Baillard & Aldrich, 2017), as well as instill graduates with a consciousness for social transformation (Wood, Hooper & Womack, 2005). This educational and research trajectory, in turn, would be congruent with a vision that scholars focused on occupation and occupational injustice: “will engage in a continuum of knowledge generation and action concerning the construct of occupation, with respect to local and global implications relevant to academia, policy and the general public” (Laliberte Rudman et al., 2008, p. 136).
2.7 References


Chapter 3  

Participatory Digital Methodologies: Potential of Three Approaches for Advancing Transformative Occupation-Based Research with Children & Youth

According to Freire (1993), “the more radical a person is, the more fully he or she enters into reality so that, knowing it better, he or she can better transform it. This individual is not afraid to confront, to listen, to see the world unveiled” (p. 21). Researchers who embody a transformative agenda seek to reveal realities of oppression faced by particular collectives, facilitate dialogue to spawn critical understandings of these realities, and collaboratively spur action towards transformation (Freire, 1993). Taking up a transformative agenda requires challenging dominant ways of knowing, where science is considered to be universally true and politically neutral (Parry, Johnson, & Stewart, 2013). It also involves shifting away from research methods that involve extracting data from subjects towards methods that demonstrate inclusion, participation, and action, and attend to issues of power, justice and equity (Bailliard, 2015). Specifically, transformative research, which ideally embodies participatory methodologies, engages community members in reflecting on and critically examining the socio-politically situated nature of shared experiences of injustices as means to address social change (Farias, Laliberte Rudman, Magalhães, & Gastaldo, 2017). This article responds to the call for methodological expansions within occupational science by exploring the potential contribution of three participatory digital methodologies with emphasis on application with children and youth. The focus on children and youth arose from not only the first author’s substantive interests, but also because it has been proposed that the involvement of children and youth in participatory projects is often constrained and these types of methodologies provide an avenue to enhance such participation (Jacquez, Vaughan, & Wanger, 2013).

Growing attention to the transformative potential of occupation-based research is reflected in the uptake of critical frameworks and concepts that embody transformative intents, such as, occupational justice (Wilcock & Townsend, 2000), occupational possibilities (Laliberte Rudman, 2010), occupational sustainability (Townsend, 2015) and occupational consciousness (Ramugondo, 2015). Increasingly, critical theories have been incorporated to highlight the situated and political nature of occupation, challenge foundational assumptions, and foster the transformative potential of occupational science (Farias & Laliberte Rudman, 2016). Methodological expansions have been identified as vital to further enact this transformative potential (Bailliard, 2015; Laliberte Rudman & Aldrich, 2017), with participatory methodologies highlighted as particularly relevant (Hartman et al., 2011; Huot & Laliberte Rudman, 2015).

Participatory methodologies strive to involve community members facing injustices as co-researchers in all phases of projects, from identification of issues to execution of socially transformative actions (Cargo & Mercer, 2008). “Participation” involves on-going negotiation of power between researchers and community members, working towards shared understanding, dialogue, and social action or transformation (Grimwood, 2015). Researchers work with, as opposed to working for, a community (Johnson & Parry, 2015), and community members are positioned as knowledge producers and social actors. Social transformation is a continual process of addressing socio-political factors shaping and perpetuating situations of injustices (Farias et al., 2017). This process can encompass a range of actions, from raising critical consciousness to enacting changes in policies, programs, social practices, or institutions (Kidd & Kral, 2005). Within participatory approaches to social transformation, researchers need to continually collaborate with community members in mobilizing change in a manner that is contextually relevant as well as sustainable (Blair & Minkler, 2009). Previous commentary and research has highlighted not only the ideals of participatory and transformative approaches, but also have raised awareness of various challenges to achieving such ideals, such as, epistemological tensions (Farias et al., 2017), insider-outsider tensions, insufficient time, and balancing cultural humility (Cargo & Mercer, 2008), which are often shaped by ethical guidelines and funding agencies (Frisby, Reid, Millar, & Hoeber, 2005).
Despite increasing attention to the potential of participatory approaches for transformative research within and outside occupational science, the use of such approaches with children and youth has been less common than with adults. However, as conceptualizations of children and youth have shifted away from paternalistic viewpoints towards those embracing children’s rights, citizenship, agency, and capacity for social action (Batorowicz, King, Mishra, & Missiuna, 2016), there have been efforts to develop participatory approaches for use with children and youth (Veale, 2005). In addition, studies addressing children’s cognition have increasingly highlighted that reasoning capacities are contextually variable, and that research processes can be understood by children and youth if presented in appropriate, engaging ways (Batorowicz, Stadskleiv, Missiuna, & von Tetzchner, 2016; Jacquez et al., 2013). The need for further development of approaches to foster child and youth participation was also identified by Jacquez and colleagues (2013) who found that only 15% of 399 community based participatory research articles published between 1985 to 2012 of relevance to children and youth positioned children and youth as research partners or co-researchers, instead relying on other stakeholders, such as parents and health care providers, to speak for and act on behalf of children and youth.

In particular, participatory digital methodologies have been suggested as adaptable to the needs and capacities of children and youth. Given that these methodologies use diverse digital technologies to position participants as co-researchers, and do not solely rely on verbal communication, they have been forwarded as means to overcome barriers to participation related not only to age (Vindrola-Padros, Martins, Coyne, Bryan, & Gibson, 2016), but also literacy levels (D’Amico, Denov, Khan, Linds, & Akesson, 2016) and disability status (Ha & Whittaker, 2016). Moreover, participatory digital methodologies have been described as having potential to foster enjoyable, engaging spaces for children and youth, and capture how children and youth understand their worlds in ways that incorporate power sharing (Ruiz-Casares, 2016).

Thus far, the application of participatory visual and digital methodologies within occupation-focused research has focused on photovoice and photoelicitation (Asaba, Laliberte Rudman, Mondaca, & Park, 2015; Hartman et al., 2011; Lal, Jarus, & Suto,
2012), particularly when addressing children and youth (Berinstein & Magalhães, 2009; Cahill & Suarez-Balcazar, 2012; Galvaan, 2015; Phelan & Kinsella, 2014) with a dearth of information on other participatory digital methodologies. Through exploring the application of three emerging participatory digital methodologies in transformative work within varied disciplines, our intent is to critically consider their relevance for occupation-focused transformative research with children and youth. We also seek to raise awareness of tensions and challenges crucial to address to optimize their participatory nature and transformative potential.

3.1 Critical Methodological Review

This paper examines the utility of digital storytelling, participatory videos, and participatory geographic information systems (PGIS) for transformative research with children and youth that addresses occupation. The focus of the review was a critical analysis of the application of the methodologies as participatory and transformative, rather than a focus on findings. It is acknowledged that the positioning of these approaches as a method or methodology are fluid and developing, but for clarity they will hereafter be referred to as methodologies.

3.1.1 Selection and brief description of methodologies

Methodologies highlighted in two key texts, specifically, Participatory Visual and Digital Methods (Gubrium & Harper, 2013) and Participatory Visual and Digital Research in Action (Gubrium, Harper, & Otañez, 2015b), acted as a guiding point to identify a set of participatory digital methodologies. A search using specific keywords corresponding to participatory digital methodologies identified with the texts (i.e., photovoice, digital storytelling, participatory videos, participatory geographic information systems, participatory digital archives, participatory design), population and subject of interest (e.g., children, youth, adolescents, occupation, engagement, doing, activity, social participation, inclusion) and research approach (e.g., participatory action research, transformative research, action research) was carried out across 12 databases (Anthropology Plus, Academic Search Complete, CINAHL, ERIC, JSTOR, Nursing & Allied Health, ProQuest Sociology Collection, ProQuest Arts and Humanities,
PsychINFO, PubMed, Scopus, Web of Science: See Table 4 for more details). The purpose of this search was to identify: a) digital methodologies commonly used in transformative research with children and youth addressing some aspect of occupation; and b) articles within each digital methodology for critical analysis. Based on the search results, photovoice, digital storytelling, participatory videos, and PGIS were identified as most commonly used. The utility of photovoice within occupation-based research has been previously discussed (Asaba et al., 2015; Hartman et al., 2011; Lal et al., 2012); therefore, the other three methodologies were selected.

Table 4. Search Strategy and Article Selection

<table>
<thead>
<tr>
<th>Database</th>
<th>Participatory Videos</th>
<th>Digital Storytelling</th>
<th>Participatory GIS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total Hits</td>
<td>Relevant Hits*</td>
<td>Total Hits</td>
</tr>
<tr>
<td>Anthropology Plus</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Academic Search Complete</td>
<td>9</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Web of Science</td>
<td>7</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Scopus</td>
<td>127</td>
<td>2</td>
<td>166</td>
</tr>
<tr>
<td>ProQuest Sociology Collection</td>
<td>36</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>PsychINFO</td>
<td>17</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>ERIC</td>
<td>27</td>
<td>0</td>
<td>17</td>
</tr>
<tr>
<td>ProQuest Arts and Humanities</td>
<td>49</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>CINAHL</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>PubMed</td>
<td>5</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Nursing &amp; Allied Health</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>JSTOR**</td>
<td>1000</td>
<td>1</td>
<td>1000</td>
</tr>
</tbody>
</table>

Total Selected Articles 9 6 5

Note. *Repeats have been removed; **An additional search through JSTOR that examined the first 1,000 hits in each methodology was conducted to identify additional examples.

As all three are emerging methodologies, we provide a brief description of each. Digital storytelling was developed in the early 1990s as both a research methodology and tool for social change (Lambert, 2009). Digital stories are 2-3-minute multimedia fragments that
combine images, texts, videos, music, and a personally narrated voice, to convey compelling experiential accounts of personal or community experiences (Gubrium, 2009). When employed within a participatory approach, efforts are made to create spaces for participants to engage in creative self-expression, critical dialogue, reflection, and action (Alexandra, 2008). Participatory video making, which has a diverse history dating back to the mid 1900s (Corneil, 2012), embodies a collaborative process of creating videos that incorporate art, storytelling, poetry, music, or drama as a means to document and critically engage with social issues, reveal hidden social relations, communicate knowledge, and stimulate collective action (Lunch & Lunch, 2006; Mitchell, Milne, & de Lange, 2012). Participatory geographic information systems (PGIS), also known as public participation and community integrated GIS, were developed in the 1990s partly in response to critiques of the use of GIS technologies in authoritative ways (Dunn, 2007; Mukherjee, 2015). PGIS uses GIS software and hardware tools to collaboratively produce and reflect on spatial knowledge, engaging community members in creating maps, sharing local knowledge, and contextualizing or ground-truthing spatial information, to affect change (Mukherjee, 2015).

Freire’s work is a key theoretical foundation for both digital storytelling (Alexandra, 2008) and participatory videos (Schenscul & Dalglish, 2015), supporting goals of facilitating critical dialogues as a means to shape change (Gubrium, 2009). The theoretical roots of PGIS also align with critical social theories, including feminist epistemologies that address gendered experiences across multiple axes of difference (Kwan, 2002).

### 3.1.1.1 Selection of articles

Inclusion criteria required that articles were: a) a research article; b) positioned in relation to a transformative research agenda; c) applied one of the 3 digital methodologies; d) carried out among children/youth, inclusive of cultural variation in age limits identified by authors; e) addressed an issue relevant to occupation (everyday activities that people do as individuals or as collectives); f) published between January 2000-March 2017; and g) written in English. A total of 20 articles were identified (6 digital storytelling, 9 participatory videos, and 5 PGIS) [see Table 5].
<table>
<thead>
<tr>
<th>Occupational Setting (e.g., Female Sexual Health)</th>
<th>Social and Emotional Education and Early Critical Thinking</th>
<th>International Influences (e.g., Issues Related to Young Lgbtq+ Youth)</th>
<th>Occupational Roles (e.g., Young Motherhood)</th>
<th>Study Purpose</th>
<th>Participant Characteristics</th>
<th>Geographical Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wood (2016) in New Zealand (ages 9-13)</td>
<td>6 Lessons on the experience of youth</td>
<td>Mixed Methods and a Survey of Youth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corthell et al. (2013) in Philadelphia, USA</td>
<td>Prevention of Violence</td>
<td>Promotion of Well-being of Youth</td>
<td>School Activities (ages 6-12)</td>
<td>Study Purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wexler et al. (2016) in South Africa</td>
<td>Prevention Initiative</td>
<td>Promotion of Well-being of Youth</td>
<td>School Activities (ages 6-12)</td>
<td>Study Purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treffers et al. (2019) in Canada</td>
<td>Prevention of Violence</td>
<td>International Influences (e.g., Issues Related to Young Lgbtq+ Youth)</td>
<td>School Activities (ages 6-12)</td>
<td>Study Purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lewis &amp; Miller (2010) in South Africa</td>
<td>Prevention of Violence</td>
<td>International Influences (e.g., Issues Related to Young Lgbtq+ Youth)</td>
<td>School Activities (ages 6-12)</td>
<td>Study Purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stimson et al. (2016) in Canada</td>
<td>Prevention of Violence</td>
<td>International Influences (e.g., Issues Related to Young Lgbtq+ Youth)</td>
<td>School Activities (ages 6-12)</td>
<td>Study Purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Park et al. (2016) in Hawaii</td>
<td>Prevention of Violence</td>
<td>International Influences (e.g., Issues Related to Young Lgbtq+ Youth)</td>
<td>School Activities (ages 6-12)</td>
<td>Study Purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Science Concepts Addressed</td>
<td>Participatory Researcher Study Purpose</td>
<td>Location</td>
<td>Country</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>--------------------------------------</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment, School Readiness, College Readiness (i.e., college preparation)</td>
<td>Youth 18-21 years, 7-10, 2-6, 6-10, 12-18 years</td>
<td>Campus</td>
<td>Cambodia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding and fostering professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Philippines</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Preparation (i.e., college preparation)</td>
<td>Expanding professional activity</td>
<td>Youth 2-6, 6-10, 12-18</td>
<td>Nigeria</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total**: 9 high-income students, 5 high-income students, 5 high-income students, 5 high-income students, 5 high-income students, 5 high-income students, 5 high-income students, 5 high-income students, 5 high-income students.
<table>
<thead>
<tr>
<th>Concept/Address</th>
<th>Geophysical Location</th>
<th>Participant Characteristics</th>
<th>Study Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational science</td>
<td>USA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>麽</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational science</td>
<td>USA</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.1.1.2 Analytical approach

After extracting descriptive details, a set of guiding questions directed multiple, critical, iterative readings, reflexive note taking by the first author, and collaborative discussions between the first and second author. Guiding questions were developed by the first two authors drawing on key principles of participatory and transformative methodologies, and an occupational science lens (Cargo & Mercer, 2009; Farias et al., 2017; Frisby et al., 2005; Grimwood, 2015; Hocking, 2012). More specifically, guiding questions addressed: a) how a particular methodology was useful and relevant for research among children and youth; b) if and how participation in the research process was demonstrated, and who was included in the process; c) if and how personal and/or social transformation was demonstrated; d) what pragmatic and ethical issues emerged; and e) how various aspects of occupation were addressed. Detailed notes addressing these guiding questions were compiled for each article by the first author, and reviewed by the second author. Themes related to participation, transformation, and occupation were generated by the first author through an iterative process of coding and comparing notes across articles, and were further refined through dialogue with the remaining authors.

3.1.2 First author reflexive positioning

Given the centrality of critical reflexivity to the quality of participatory methodologies (Whittemore, Chase, & Mandle, 2001), reflexive notes with regard to first author’s positionality are articulated prior to describing key findings. The remaining authors, as members of the first author’s comprehensive examination committee, provided on-going mentorship.

My interests in exploring participatory digital methodologies for transformative research among children and youth grew out of particular experiences as an occupational therapist working among children and youth within a developing region of the world. I found myself questioning the socio-political forces that positioned children with disabilities as the marginalized “other” within society and created barriers to occupational participation. My research experiences sensitized me to how research in this context often focused on exploring
perspectives of families, service providers, and community members, implicitly positioning children with disabilities as “inexperienced, passive and intellectually immature” (Singh & Ghai, 2009 p. 132). As an occupational therapist and scientist, I believe that children with disabilities need to be provided opportunities to share their occupational experiences to guide social change. With this conviction, I was urged to learn about emerging research methodologies that could be used to collaborate with children and youth, with and without disabilities, from across cultural contexts.

3.2 Findings

Three central areas for consideration emerged through the analysis: “working towards participation of children and youth”, “enacting personal and social transformation”, and “insights regarding occupation”. We highlight strengths of each methodology, as well as challenges evident in attempts to apply them in participatory and transformative ways.

3.2.1 Working towards participation of children and youth

Across methodologies, variations in the degree to which children and youth participated, either in self-defined ways or within designated research roles, in the continuum of research to action were evident, with their participation appearing most limited in PGIS articles. Within digital storytelling projects, participation ranged from youth co-developing their roles to being restricted to particular roles by researchers. At one end of this continuum, the youth in Fletcher and Mullet’s (2016) project helped lead workshops and were involved in processes of planning, designing, evaluating, and disseminating stories. In contrast, student participants in Wood’s (2016) project were only partially involved even in creating their stories. Youth identified and examined issues through taking and reflecting on photographs, however, most digital stories were created by school teachers. In participatory video making projects, overall, children and youth participated in many aspects of video making and dissemination processes, but it was common for adult researchers or participants to take over responsibility, or provide more assistance, in editing processes. For example, in Grasser and colleagues’ (2016) project, children identified themes, wrote stories, and interviewed community members using
cameras. However, workshop leaders carried out the first raw editing, finalized the video, and “presented the results to the children” (p. 7). There were some exceptions, where youth members were involved in either the initial rough editing process (Haynes & Tanner, 2015) or the entire video editing process (Tang & Jardine, 2016). PGIS projects appeared to largely adopt an “expert-facilitated” approach (Gubrium & Harper, 2013). In most instances, researcher-constructed boundaries were evident, with children and youth participation often largely confined to data collection activities. For example, in Literat’s (2013) project, student participants were given maps, and researcher-generated instructions on how to color-code their environment in relation to level of comfort. Although youth were trained to interpret digital maps, the maps were ultimately “collected by the researcher-facilitator for visual analysis” (p. 203).

Variations in how children and youth participated within different projects were often shaped by social and pragmatic barriers and tensions faced by researchers during project execution. For instance, challenges and tensions associated with power sharing and achieving participation were evident. For example, in Luchs and Miller (2016)’s project, despite an initial aim for youth to assume full responsibility in knowledge mobilization, the facilitators seemed to take up a paternalistic stance and increasingly made decisions on behalf of youth. More specifically, within a context of having youth answer audience questions, these authors stated, “our first instinct was to ‘protect’ the youth presenters and avoid a question and answer period” (p. 445) and then they decided to “permit questions but proceed cautiously” (p. 446). In some instances, a lack of on-going negotiation between adults and children and youth influenced stories created in ways that worked against study aims. For example, Hoechner (2015) recruited a professional adult script advisor to guide almajirai, indigenous students with story writing and acting. This advisor made several key decisions, such as hiring professional adult actors, and made script edits that situated the students’ problems as active individual choices. Students did not appear to have the space to oppose, or negotiate with the advisor, and the final video which “bore fingerprints from a number of people who weren’t almajirai” (p. 641) may have perpetuated negative stereotypes of the almajirai that the research was trying to challenge.
Across methodologies, the social and pragmatic barriers to participation of children and youth, included, parental resistance (Blazek et al., 2015); time commitment required from youth (Hoechner, 2015); fears of being in front of the camera and approaching others to be in front of the camera (Riecken et al., 2006); and poor technological literacy among youth (Hoechner, 2015). Such challenges worked against participatory ideals, as well as posed ethical questions when they resulted in restricted participation. For example, in Wood’s (2016) project, a proposed community youth street festival, planned as a venue for youth to challenge negative stereotypes about their riskiness to society, was cancelled due to the lack of funds for additional security as the “event had become too risky” (p. 316). Therefore, despite the author’s intention for social change, it was difficult to “separate this school community from its historic and spatial legacies” (p. 318), and the youth were unable to challenge their construction as risky. In another example, time constraints prevented youth from being involved in the interpretation phase, which raised ethical concerns regarding researcher misinterpretation of visuals (Topmiller et al., 2015).

Other ethical tensions emerged related to the representations of children and youth. For example, in Hoechner’s (2015) project a student who acted as a thief within the participatory video expressed that “he was afraid that people in his village… would not be able to tell reality and fiction apart” (p. 644). In Dennis and colleagues’ (2009) project, children and youth often worked with images that reflected illegal or illicit activity. Although the research team decided to delete such images, they pointed out that “memories of the discussions remained and were difficult to ignore” (p. 471), highlighting ethical issues related to confidentiality and safety of people depicted within photos as well as that of photographers. Related to balancing acknowledgement with confidentiality, Tang and Jardine (2016) articulated tensions between providing film credits and preserving youths’ confidentiality in the final visual product. Overall, each methodology was used to engage with children and youth experiencing diverse situations of marginalization, although children with disabilities who can be framed as experiencing marginalization were involved only in one project (Shamji, 2007). Additionally, digital storytelling and participatory video projects were carried out across various geographic contexts, with young people considered out-of-place and from the “wrong side of the tracks” (Wood, 2016, p. 310), First Nations/Indigenous/Native youth (Riecken et al.,
2006; Tang & Jardine, 2016; Wexler et al., 2013), refugee youth facing negative societal stereotypes (Luchs & Miller, 2016), young Latina parents who were being blamed for their life conditions (Gubrium et al., 2014b), and youth not fluent in English and not familiar with digital cameras (Hoechner, 2015; MacEntee, 2016). PGIS projects, however, were carried out predominantly within USA, but involved youth from racial minorities (Akom et al., 2016; Literat, 2013; Topmiller et al., 2015), and from socio-economically disadvantaged residential areas (Dennis et al., 2009; Topmiller et al., 2015).

The wide applicability of these methodologies across geographical contexts as well as with children experiencing varied situations of marginalization was facilitated by the adaptability of all three methodologies. For example, to address the sensitive topic of youths’ understandings of HIV and AIDS, MacEntee (2016) adapted the digital storytelling process so participants could utilize drawings instead of photographs and worked in three single-sex groups. Fletcher and Mullet (2016) facilitated the participation of Indigenous youth residing in physically dispersed communities by using a “mobile digital storytelling process” in which a mobile media van was taken to communities for workshops. Frey and Cross (2011) used video production, along with dramatization, to support youth in communicating experiences of school abandonment, which they found especially difficult to articulate through tasks such as reading and writing that were often linked to their experiences of “school failure”. A unique strength of PGIS includes its potential to facilitate virtual collaboration. In Akom and colleagues’ (2016) project, the Streetwyze platform, a “mobile mapping, and SMS tool that collects real time information about how people are experiencing cities and services” (p. 1294), was used by physically dispersed students to digitally organize and communicate their information in real time.

### 3.2.2 Enacting transformation

Consistent with the aims of participatory digital methodologies, all projects embodied transformative goals, although with more attention to personal rather than social transformation. However, even within projects claiming personal transformation related to knowledge, skills, self-perceptions and social awareness among youth, there was often little to no integration of youth’s voices to support such claims. As illustrations, Literat
claimed that youth empowerment may have been stimulated in their PGIS project through creating spaces for youth to discuss sensitive community issues and advocate for social action, while Luchs and Miller (2016) shared researchers’ observations that youth clarified complex issues for themselves via engagement with audiences regarding their digital stories. However, more convincing, collaborative demonstration of personal transformation was presented in a few articles. Within Fletcher and Mullet’s (2016) digital storytelling project youth articulated that they had developed a sense of belonging, been given a space for their voices, and built self-esteem. In a PGIS project, Akom and colleagues (2016) shared youth’s voices from exit interviews to highlight ways youth gained critical knowledge on the contextual forces influencing food access issues.

Transformation is an ongoing process and participatory approaches mandate researchers to continually collaborate with community members in all phases of the research as well as action processes (McTaggart, 1991). Although personal transformation that embodied consciousness raising and fostering a passion for social change surfaced within digital storytelling and participatory videos projects, ethical concerns were raised when this was not followed to completion by continued support for youth in enacting social transformation. For example, Wood (2016) highlighted how youth participants’ digital narratives pointed to the development of critical consciousness about community issues and a sense of agency as political actors, but no further action was reported after the youth took their ideas to local council. In contrast, youth participants in Haynes and Tanner’s (2015) who had created a participatory video on illegal quarrying and deforestation moved forward with actions in collaboration with community members who viewed the video and worked with government representatives to ban illegal logging and mining occupations.

Within both digital storytelling and participatory video projects, the most prevalent ways of attending to social transformation involved changing attitudes and challenging negative stereotypes. For example, in their digital storytelling project, Wexler and colleagues’ (2013) highlighted that Native youth deflected perceived stereotypes through visually portraying how their lives were culturally situated. In a participatory video project, Frey and Cross (2011) used their video to challenge teachers’ existing notions
about reasons for school abandonment and to collaboratively propose actions. In a few participatory video and PGIS projects, attempts were made to extend social transformation into system, practice and institutional changes, such as creating a non-profit organization to address study-generated objectives (Ritterbusch, 2016), integrating youth into medical clinic orientations (Dennis et al., 2009), and providing farmers’ markets at school sites (Akom et al., 2006). However, authors pointed to various challenges faced when attempting social transformation, such as long-standing historically shaped negative perceptions (Wood, 2016) and temporal limits and resistance to collaboration by particular stakeholders (Frey & Cross, 2011).

3.2.3 Insights regarding occupation

Although none of the included articles explicitly incorporated an occupational perspective, the projects addressed diverse occupations such as traditional Indigenous occupations, mothering, drug use, dancing, being a student, play, and others (see Table 5). Overall, findings generated knowledge relevant to understanding occupation as situated as well occupational injustices.

First, given the grounding of these methodologies in critical perspectives, they often generated knowledge relevant to understanding occupation as situated. For example, Gubrium and colleagues’ (2014b) used digital storytelling with young mothers to enhance understanding of how the occupations of these mothers were shaped through contextual forces. Specifically, problem-oriented and stigmatizing discourse(s) of young motherhood related to “structural violence, notions of fit parenting, and youth-directed sexual politics” (p. 339) were analyzed in collaboration with young mothers with the aim to shift focus from individual choices to one that included systemic forces (economic, cultural, structural). In Blazek and colleagues’ (2015) project, the participatory video, entitled “Kopčany: neighbourhood needs a playground” (p. 45), enhanced awareness of the ways that neighbourhood spaces failed to support the occupational role of the participants as “carers” of young children. Project participants cared for younger children on a regular basis, which was an important part of their life in the neighbourhood. They identified that the children they cared for lacked suitable places to play in within their neighbourhood environment, and sough to address that need through their participatory
video. Given the geographical focus in PGIS, such projects often attended to youths’ occupational experiences as situated within specific spaces. For example, in the project by Literat (2013), youth participants associated their “comfort spaces” with leisure occupations, such as soccer fields or gaming arcades. Akom and colleagues’ (2016) study generated knowledge regarding socio-political forces shaping issues of food insecurity experienced by young people in a specific neighbourhood. For instance, findings revealed a lack of grocery stores within their communities leading to youth experiencing food deserts, and in turn, engaging in occupations of securing unhealthy food from existing corner stores. Furthermore, youth generated solutions to identified issues addressed occupations of securing healthy food, such as, calling for existing corner stores to stock organic and locally grown fresh produce, participate in food stamp and other related programs, as well as limit tobacco and alcohol advertising and promotions.

In addition, projects often generated knowledge and raised awareness of diverse barriers to occupations, thus addressing occupational injustices. Within Wood’s (2016) digital storytelling project, youth identified dysfunctional occupational spaces, such as inadequate playground facilities and a polluted river, which lead to “a sense of injustice” (p. 319). Frey and Cross’s (2011) participatory video project addressing school abandonment raised awareness of contextually situated challenges faced by marginalized youth, such as, poor school infrastructure, lack of commitment of teachers, verbal and physical mistreatment and, repetitive classes that prevented their participation in school, and in turn, led to their school abandonment. Extending the dialogue on occupational justice to incorporate issues relevant to occupational degradation (Townsend, 2015), youth from Haynes and Tanner’s (2015) project explored how occupational practices, such as illegal logging, chromite mining and deforestation activities, contribute to climate change. Furthermore, their videos interestingly revealed and raised community discussions surrounding socio-political forces shaping issues of injustices experienced by certain collectives who participate in mining occupations and are exposed to risks but receive no benefits that some others receive from their mining.
3.3 Discussion

This review demonstrates that digital storytelling, participatory videos, and PGIS have the potential to support occupational scientists in involving children and youth in transformative research, while pointing to particular tensions and challenges that are important to negotiate. A particularly significant finding is that all three methodologies, even when not informed explicitly by an occupational perspective, facilitated an understanding of occupation as situated as well as addressed occupational injustices. Thus, these methodologies appear to be ways forward in facilitating understandings of occupation beyond a dominant individualistic frame (Cutchin & Dickie, 2012; Laliberte Rudman, 2013) that, in turn, can inform socially transformative practices (Farias & Laliberte Rudman, 2016).

More specifically, these methodologies offer ways for occupational scientists to expand research beyond a dominant focus on occupations normative within Western, Anglophonic, and middle-class contexts (Hocking, 2012), helping to expand the figured world of occupations (Kiepek, Phelan, & Magalhães, 2014) and “unsettle established ‘truths’ about disadvantaged groups” (Hocking, 2012, p. 62). The methodologies were creatively adapted for diverse geographical and cultural contexts, and were able to further understandings of non-sanctioned occupations, such as drug use and teenage mothering (Hocking, 2012). Moreover, despite varied success in facilitating participation, projects aligned with all three methodologies supported involvement of children and youth within situations of marginalization, encompassing diversity in relation to age, social status, languages spoken, and literacy levels. At the same time, it appears that a particular contribution that can be made by occupational scientists is that of further supporting the inclusion of children with disabilities as collaborators within research and action processes, thus working against ableist assumptions regarding occupations and facilitating social transformations that are inclusive of diverse abilities.

Although participatory digital methodologies are underpinned by value-based commitments to participation, this analysis illustrates that achieving “full” participation is a complex, on-going process requiring continuous negotiation of power, critical alertness of contextual features, and proactive consideration of pragmatic barriers. Consistent with
other commentaries highlighting challenges to power sharing in participatory research with children and youth (Akesson, et al., 2014; Phelan & Kinsella, 2011), projects across methodologies highlighted power imbalances, such as when researchers limited children and youth participation to specific research phases or provided researcher-defined objectives. A specific consideration raised for future applications of such methodologies by occupational scientists is the importance of recognizing, and negotiating, challenges to power sharing in relation to contextually situated socio-cultural perceptions about children and youth’s position in society, such as when their positions defy conceptualizations of autonomy embedded within a Western worldview (Hart, 2008; Twum-Danso, 2009). For instance, although Hoechner (2015) aimed to create space for almajirai students to speak their concerns with the researcher, students were not comfortable with this position as within their sociocultural context: “one doesn’t tell one’s superior – he could get angry” (p. 643). Thus, it is important for occupational scientists to be reflexive about the socio-cultural context of a project (Twum-Danso, 2009), and exhibit caution and transparency about how “participation” is defined, so as to avoid imposition of a particular vision of participation informed by Western ideals.

Participatory digital methodologies are often situated within a critical epistemological framework, seeking to challenge and transform taken-for-granted norms, structures, and practices that perpetuate injustices (Gubrium & Harper, 2013). Within this analysis, projects commonly claimed aspects of personal transformation of children and youth participants, with socially transformative outcomes addressed to a lesser extent. Although personal transformation was proposed to involve enhanced critical consciousness among children and youth and community members, and a few projects offered up useful examples of social transformation, there was often a vagueness or silence regarding if and how action plans would be formed or supported through continued collaboration. This raises a key question for work in occupational science that takes up these methodologies: what next after the raising of critical consciousness? If actions after the raising of critical consciousness are left unaddressed, it can inadvertently place the impetus for social change into the “hands of those most affected by the issue” (Johnston, 2016, p. 799) and run “the risk of (re)orienting transformative efforts toward fixing the individual instead of addressing the social structural issues that shape peoples’ lives” (Farias et al., 2017, p. 4).
Although acknowledging barriers to participatory and transformative forms of research that are often posed by grant agencies or ethical review boards (Frisby et al., 2005), this critical analysis reflects a pressing need for occupational scientists to fully embrace the intent of participatory digital methodologies as means to enact social transformation, while raising awareness of the challenges faced in attempting to do so.

Participatory approaches with children and youth may seem attractive on the surface but may end up involving them in a process of regulation (Gallacher & Gallagher, 2008) or embodying tokenism in ways that perpetuate marginalization (Hart, 2008). Two key ethical tensions that emerged, related to unachieved participatory goals, are highlighted as key considerations for future applications of these methodologies. First, one key ethical issue that surfaced, connected to a common lack of participation of children and youth in data analysis, relates to issues of interpretation and representation. Akesson and colleagues (2014) argue that failing to involve children in the interpretation of their visual information is unethical because adult researchers come from a different position and cannot represent a child’s way of seeing. Moreover, given that visual products created by children and youth can carry different meanings for different audiences (Besteman, 2015), ethical tensions with regard to the (re)presentation of visual information created by children and youth are likely to arise. For instance, such tensions surfaced in the project by Luchs and Miller (2015) when youth, who were involved in sharing their digital stories at various schools, faced questions from audience members that potentially further perpetuated negative stereotypes of refugees and that reflected a lack of understanding of the youths’ key messages. Negotiating tensions related to the (re)presentation of visual information requires critically attending to issues such as where the visual information is disseminated; who has access to the information; and if the information can be easily re-used and re-disseminated by others (Gubrium et al., 2015a). Therefore, contextualizing visual information through involving children and youth in analysis and dissemination processes, along with establishing collaborative norms related to ownership and circulation of visual information, are vital practices to be taken up by occupational scientists (Gubrium et al., 2014a; Gubrium et al., 2015a).
Second, a key ethical tension requiring on-going critical reflexivity is that of balancing the anonymity and confidentiality of children and youth participants with an ethic of acknowledging voices and contributions (Lomax, 2015). Although it is important for children and youth participants to be acknowledged (Lomax, 2015), Gubrium and colleagues (2014a) highlight the need to consider the rights and well-being of people included within visuals as well as that of co-researchers who may depict information that could expose themselves and others to harm, as exemplified in the study example (Dennis et al., 2009) in which youth worked with images that reflected illegal activities. In addition, the risks and benefits for children and youth within dissemination processes are complicated by technological advancements that enable digital information to be edited, repurposed, and widely disseminated (Gubrium et al., 2015a). Given the complexity of representational issues, D’Amico and colleagues (2016) emphasize the importance of engaging in on-going collective reflexivity with children and youth so that they can think through the risks and benefits of creating and sharing their stories (Gubrium et al., 2014a). Gubrium and Harper (2013) articulate a key guiding question for researchers to reflect on when addressing this ethical dilemma: what is gained when participant’s confidentiality is protected, and what is lost when they do not claim the knowledge produced?

Overall, although this review was bounded in its attention to three participatory methodologies, it is acknowledged that other methodologies exist that are likely relevant to the study of occupation and to enhancing participation of children and youth. A strength of this analysis is that it clearly shows that the adoption of a methodology that is named “participatory” does not automatically lead to the achievement of participation nor the realization of transformation. This message is essential to attend to in order to avoid superficial or unreflexive uptake of participatory processes. Participatory digital methodologies provide a set of values, theoretical underpinnings and practices that are commensurate with facilitating participation and working towards transformation and must be combined with on-going reflexivity regarding issues of power and ethics. As such, moving forward in enacting participatory, transformative scholarship in occupational science needs to combine methodological expansion, such as participatory digital methodologies, with thinking “deeply about what we are doing and what we are
saying about what we do” (Cheek, 2010, p. 100). Reflecting on the limitations, strengths and challenges raised in previous work provides one avenue forward for occupational scientists to work towards setting up and carrying out participatory, transformative projects in ways that maximize alignment between ideals and practices.
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Chapter 4

4 A Participatory Filmmaking Process with Children with Disabilities in rural India: Working towards Inclusive Research

4.1 Introduction

Globally, children with disabilities are at risk for experiencing exclusion within their communities (UNICEF, 2013). This exclusion is often reproduced within research (Jones, 2007), which may be linked to assumptions of incapability (Wickenden & Kembhavi-Tam, 2014). Researchers may wrestle with skepticism related to children’s capacities (Lundy, 2007), issues of power, and the many unknowns regarding how to include children with disabilities within research, which is further superimposed by fears related to the efforts and resources needed to collaborate with them (Wickenden & Kembhavi-Tam, 2014). In turn, children with disabilities have been traditionally positioned as passive research subjects rather than as active collaborators (Gray & Winter, 2011).

However, consistent with Article 12 of the United Nations Convention on the Rights of a Child which emphasizes the need for children of all abilities to be involved in decision making related to matters affecting them (United Nations, 1989), there is a growing interest in inclusive research practices that include children with disabilities in sharing perspectives and advancing solutions on issues concerning them (Gray & Winter, 2011; Wickenden & Kembhavi-Tam, 2014). Additionally, the ‘nothing about us without us’ movement by the international disability community also explicitly makes a call for people with disabilities, including children, to be given spaces in society as equal citizens with decision making power (UN Chronicle, 2004). From a critical paradigmatic

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perspective (Ponterotto, 2005), involving children with disabilities as co-researchers within research processes can enable creation of alternative stories that challenge the status quo characterized as “a world filled with (mis)representations of disability” (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015, p. 516). Lundy (2007) has proposed four components to better support the involvement of children of all abilities in decision making processes affecting their lives: providing a \textit{space} for children to express their views; a facilitation of their \textit{voices}; an \textit{audience} to listen to their perspectives; and an \textit{influence} to mobilize action based on their views.

Participatory methodologies are one approach to research that can provide a space for children to be co-researchers through disrupting power differentials between adult researchers and children, positioning childrens’ perspectives as central to guiding research processes (Watson & Fox, 2018). However, involving children, with and without disabilities, as co-researchers requires adapting research methods to expand the understanding of voice beyond verbal or written communication (Alderson, 2008). Visual research methodologies have been acknowledged as one way of creating alternative spaces for communication and collaboration (Patton, Higgs & Smith, 2011), and are positioned to support inclusive research practices with children (Wickenden & Kembhavi-Tam, 2014) and mobilize transformative research agendas (Ritterbusch, 2016). Consequently, there has been an increase in the uptake of photoelicitation and Photovoice in research with children with disabilities (Ha & Whittaker, 2016; Nguyen, Mitchell, de Lange & Fritsch, 2015; Phelan & Kinsella, 2014; Wickenden & Kembhavi-Tam, 2014); however, with a few exceptions (Shamji, 2007), little research has been conducted on utilizing participatory video or filmmaking (Benjamin-Thomas, Laliberte Rudman, Cameron & Batorowicz, 2018).

In this paper, we share the participatory filmmaking process of creating the short film \textit{Oorai Kaatha Pasanga} (translated to \textit{Boys Who Protect Their Village})\textsuperscript{6}. This short-film was created within a participatory action research (PAR) project with children with

\textsuperscript{6} https://youtu.be/sPyiQCj82Qs
disabilities from a rural village in Southern India utilizing participatory filmmaking. Specifically, we aim to present a transparent account of the different phases of this project and the activities carried out within each phase, pointing to ways this process was modified in relation to contextual features and challenges. Through our description of this process, this work provides a response to the identified need for examples that explicate how researchers have attempted to include children with disabilities as collaborators because often their “involvement is poorly defined, and methods inadequately reported” (Bailey, Boddy, Briscoe & Morris, 2014, p. 506). The transparency of this complex yet flexible process can support other researchers when they are thinking about ‘how’ participatory research can be carried out with children with disabilities.

We first contextualize this project by briefly describing participatory filmmaking as a research methodology with particular utility within inclusive research practices with children with disabilities. Subsequently, the first author’s reflexive positioning within this research and the research context is explicated. We then present details of the different phases, and activities carried out within each phase of this participatory filmmaking process. We also share key contextual challenges faced during this process and adaptations made to address these challenges. We conclude by discussing the responsibilities researchers need to embrace when utilizing participatory filmmaking for inclusive research practices.

4.2 Contextualizing the Project

4.2.1 Methodology

Participatory video or filmmaking is a collaborative process where community members use cameras to document, explore, and critically engage with social issues through creating a film that reveals hidden social relations, communicates information, and stimulates collective action (Gubrium & Harper, 2013; Mitchell, Milne & de Lange, 2012). Consistent with critically-informed participatory methodologies, participatory filmmaking is recognized as a research methodology and a tool for community development (Mitchell et al., 2012; High, Singh, Petheram & Nemes, 2012). As a research methodology, its theoretical underpinnings include Freire’s work in critical
pedagogy (Schensul & Dalglish, 2015; Waite & Conn, 2012) and feminist theories (Waite & Conn, 2012), both focused on creating spaces for marginalized groups to voice concerns through dialogue and shared reflection as a means to mobilize change. This is based on the assumption that “when the most marginalized themselves are engaged in identifying the issues that affect them and the possible solutions for addressing them, the interventions are more likely to work” (Moletsane et al., 2009, p. 329). In addition to contributing to social transformation, personal transformation can also be enabled through the reconstruction of personal experiences (Moletsane et al., 2009) and the gaining of technical skills.

Broadly, the steps within a participatory filmmaking process encompass: collaborative brainstorming of ideas, getting to know the camera, storyboarding, working with the camera, shooting, viewing videos after the shoot, and post-production follow up (Mitchell, 2011). There are, however, different approaches to participatory filmmaking, which can vary in terms of the types of films created (e.g., documentary, fictional), methods used for making films, and types of editing approach (e.g., no editing-required, with editing, or a live first take) (Gubrium & Harper, 2013; Mitchell, 2011). As such, there is no one way of carrying out this methodology as the process needs to be adapted to the cultural context, the participants, and the community context.

Although participatory filmmaking has not widely been used with children with disabilities (Benjamin-Thomas, Laliberte Rudman et al., 2018), it is proposed that this methodology can open spaces for understanding socio-political contexts shaping issues concerning children with disabilities and their communities from their often-neglected point of view. In fact, “art can sometimes be used to trouble the embedded and taken-for-granted relations of disability. Drawing on the arts can force us to relate radically to disability in ways not easily available to us in our everyday lives” (Ignagni & Church, 2008, p. 631). Although participatory filmmaking can promote inclusive research practices and stimulate social transformation, this methodology in and of itself “holds no guarantee of truth or liberation. It never completely exposes the invisibility, the darkness or the unknown” (Tilleczek & Loebach, 2015, p. 356). Thus, in carrying out such
projects, there is a need for on-going modification to ensure key underlying principles are attended to in contextually relevant ways and that efforts extend to mobilizing action.

4.2.2 Researcher positioning

Researcher reflexivity, involving engagement in explicit self-awareness of one’s thoughts, roles, feelings, actions and positionality (Finlay, 2002), is central to quality within critically-informed research (Whittemore, Chase & Mandle, 2001). The process of inward reflexivity, and reflexivity addressing situatedness of self and project in context, facilitates exploration of how a researcher’s personal experiences and values, shaped by dominant socio-political and cultural forces, have an influence on his/her research interests and research processes (Berger, 2015). This process of ongoing reflexivity, which ideally starts from project inception (Finlay, 2002), supports researchers in questioning dominant ideologies, as well as in enacting change (Phelan, 2011). To better contextualize this project, the first author, shares reflexive notes regarding her positioning, making transparent the intentions for doing this work and the rationale for using this methodology within this PAR project.

I write from the position of being a woman of South Indian origin, but currently located within a North American institution pursuing my PhD education. This project was carried out as a part of my PhD thesis work within the field of occupational science. This work came out of my dual interests of working as an occupational therapist with children with disabilities and advocating for their rights and inclusion, and my interest in using creative and innovative methods and methodologies for mobilizing transformative research agendas. I have always believed that visuals can be powerfully used for amplifying voices seldom heard in media, which are important voices for challenging the status quo and stimulating change. Situating my experiences in filmmaking, I want to clarify that I am not a professional filmmaker and neither have I had any formal training in filmmaking. However, with that being said, I have experiences in creating short films for personal as well as some professional work, and I would call myself a self-taught film editor. These novice filmmaking skills coupled with my interests
in filmmaking and photography helped propel this participatory filmmaking project.

Additionally, I want to make transparent my relationship with the local institution through which this project was carried out. I did my undergraduate education within this institution in India and was familiar with the villages it serves. Moreover, I am fluent in speaking Tamil, the language spoken within these communities, as it is my mother tongue and I grew up speaking Tamil with my family. Language fluency played a central role in building relationships, and in turn, collaboration. However, in spite of me speaking the same language and being from the same ethnic group, I was still constantly navigating my varied positions as both an insider and outsider (Merriam at al., 2001) as I come from a very different background having grown up in a metropolitan Indian city, holding different educational and life experiences.

Based on my experiences as a pediatric occupational therapist, I believe that children with disabilities are positioned as social actors who should be provided with a space for their perspectives to be heard and acted on. Participatory filmmaking is a tool that I perceive can be used to guide inclusive research practices, as it works towards breaking down power differentials and creating a space for alternative means of communication. Moreover, films are powerful visuals that can be used to mobilize social change.

4.2.3 Research context

This project was carried out through a community health department of a Medical College and Hospital in India. Since the 1960s, this department has encompassed a network of healthcare professionals who provide health, development, and training services in a geographical area encompassing approximately 85 villages (Muliyil et al., 2018). This PAR project was carried out in one village within this geographic area, which encompasses a population, according to the 2011 census, of just under 5,000 people (Indian Village Directory, 2019).
4.3 Overview of the Participatory Filmmaking Process: Creating Oorai Kaatha Pasanga

This PAR project involved six male children (aged 10-17 years), who were identified by health care practitioners or their community members as having disabilities (visual impairment, speech and hearing impairment, intellectual disability, or no formal diagnosis), as co-researchers. Although the project recruitment was open to males and females, it is not known why only males were identified for this project within this community. The objectives of this project were to: a) explore first-hand perspectives from children with disabilities about if and how they participated in occupations (i.e., the everyday activities within the context of their daily lives); b) support them in identifying barriers and supports related to occupational participation; c) support them in envisioning what change they needed and wanted related to everyday occupation; d) work with them and key community stakeholders towards addressing identified barriers and mobilizing community change.

Overall, children with disabilities collaborated with the first and third author (facilitator and co-facilitator of study process) in selecting the methodology of participatory filmmaking; identifying and prioritizing issues they were concerned about within their communities; creating narratives about the identified issues; capturing relevant video clips; and co-editing the short film with the first author. This film shares first-hand perspectives about issues within their community surrounding: a) teasing, bullying, and marginalization of children with disabilities within schools and the larger community; b) garbage accumulation; c) substance abuse by adults and youth; and d) deforestation.

This PAR project was broadly divided into three phases, and the details for each phase are described below (see Figure 1). The first author travelled to India for the preparatory phase and remained in the context for 8 months until completion of the participatory research phase and the initiation of the action phase. This research project obtained ethical approval from the Western University Health Science Research Ethics Board, London, Canada (Project ID: 110912) and the Institutional Review Board Christian Medical College, Vellore, India (IRB No: 11191).
4.3.1 Preparatory phase

4.3.1.1 Strengthening local collaboration

Although the primary/first author had established connection with the local collaborators (i.e., one physician and two occupational therapists from the collaborating institution in India) virtually, the project was officially initiated after she travelled to India. She had regular in-person meetings with local collaborators to discuss the broad project objectives, and the values and central tenets of equitable collaboration and social transformation this PAR sought to embrace (Benjamin-Thomas, Corrado, McGrath, Laliberte Rudman, & Hand, 2018). The first author worked with them in collaboratively finalizing team member’s roles. Additionally, the first author reached out to potential volunteers with skills in photography and filmmaking to explore their interest in providing training to the children.

4.3.1.2 Recruitment of children with disabilities

When ethical approval for this project was obtained from required institutions, the first author visited four villages with a local occupational therapist, who identified these villages based on his knowledge about village demographics and the potential to host this project. We sought to identify a group of children from the same community to work together on this collaborative project. Through this process, one village, which had 6-9 children with disabilities, was collaboratively identified.
Recruitment efforts within the identified village, using culturally and linguistically relevant posters and recruitment meetings, were mobilized with the help of a community health aide, who was a member of that village that worked for the local collaborating institution. The community health aide visited the houses of children with disabilities who fit the inclusion criteria and handed out posters about this project along with the letter of information, and the parents and children were invited for a recruitment meeting. After a two-week period, the recruitment meeting was conducted within their village with parent(s) of eight children, and six children were present. During this meeting, the first author presented the details of this project, went through the letter of information, and addressed questions parents or children had about this project. Parent(s) of six children were interested and provided written consent for their child’s involvement. The parent(s) of the other two children had expressed needing more time and were asked to connect with the local health aide if they were interested at a later point. This meeting was followed up with a subsequent session with just the children to share information about this project and to obtain their assent for involvement.

4.3.1.3 Selection of equipment

The selection of equipment for the video making processes was based on the resources available for this project. The first author along with a professional photographer (third author) engaged in numerous discussions about the different kinds of cameras that might be needed, especially since the videos were going to be captured in ways that were unidentifiable. Digital single lens reflex (DSLR) cameras were discussed as tools that could aid in creating de-identified videos as they provide a depth of field and enable blurring of backgrounds easily. However, they were expensive and not easily accessible within the scope of this project, as cameras for this project were borrowed from friends and family by the first author. After consulting with a videographer, we decided to use point and shoot digital cameras. Six cameras were gathered for use within this project, and one of the six cameras was a mirrorless camera which can be considered as a bridge camera between a DSLR and a point and shoot. Additionally, we had one gorilla tripod as well as the first author’s laptop, a MacBook Pro, to use for film editing.
4.3.2 Participatory research phase

4.3.2.1 Rapport building

As Alderson (2008) states, “a striking aspect of children’s research is the combining of work and play” (p. 284), and ‘fun’ was a key component to support children’s role as collaborators within this research project. Thus, the initial phase focused on building rapport and trust with the children through fun activities and games, including, hide and seek in the paddy fields or the temple area; a game of cricket using sticks as the wicket stumps; follow the leader game with Tamil kuthu (trans. upbeat) songs; and others. To better promote the full involvement of children with disabilities, we adapted the games to make them more inclusive by methods such as using visual cues in addition to auditory information to facilitate participation of a child who had a hearing impairment and experienced difficulty with verbal communication. We also adapted games to sensitize our group of children about the needs of their peers within the group. For example, colourful headphones were used, and white noise was played in the background, and each child had a chance to wear the headphones and simultaneously listen to what the other children were trying to communicate. This game helped children understand the experience of their friend and group member who had a speech and hearing impairment. Incorporating ‘fun’ into this process played a central role in not only building trust and rapport but also in facilitating learning.

4.3.2.2 Identifying and prioritizing issues

Additionally, group meetings provided children with information about the project (i.e., its focus on issues related to occupation) and its proposed methodologies (i.e., participatory filmmaking or digital storytelling), which was done through the use of age and culturally appropriate activities. For instance, relevant illustrations on ‘occupations’ (i.e., the everyday activities that we need and want to do) within this cultural context were drawn specifically for this project and were printed as stickers. Children sorted these stickers based on whether they liked doing these occupations or not (see Figure 2), which initiated discussions about the concept of ‘occupations’. As a next step, we used Post-it stickers to help children jot down the different occupation-based issues they
wanted addressed through this project, and consequently used a tree diagram to help prioritize these issues, with the issue of highest priority placed on top (see Figure 3). After a few meetings, children collaboratively established the themes of focus for this project by choosing topics of concern at the individual and community level (i.e., teasing, bullying, and marginalization, of children with disabilities; garbage disposal; substance abuse by adults and children; deforestation).

Figure 2. Sorting Culturally Relevant Visuals about Occupations
4.3.2.3 Choosing a methodology

When issues were being explored, children were provided two methodology options, specifically, the use of either digital storytelling (a process that involves creating short 2-3-minute multimedia fragments with images, videos, texts, music, and a narrated voice to convey personal or community experiences: Gubrium, 2009) or participatory filmmaking (a collaborative process of engaging in social issues through creating a shared film: Gubrium & Harper, 2013). We differentiated these methodologies based on whether children wanted to create individual video narratives (i.e., digital storytelling) or a group video (i.e., participatory filmmaking). Participatory filmmaking was the choice made unanimously by the children as all of them preferred to work on a shared group project.

4.3.2.4 Training of children

A genuine barrier to children’s participation in research is not their lack of competency, but a lack of research skills that can be attained through training (Kellett, 2011). Within this process, children with disabilities were provided initial training on camera use and
visual research ethics. Training on camera use encompassed how to: hold a camera, turn it on, focus the image, use the rule of thirds, learn manual functioning details, record video clips, pan videos, and use of efficient lighting. For most children, this was their first time using a camera, but they were very quick at learning basic camera skills. The local professional photographer involved in this project, initially as a volunteer but later as a co-investigator, helped with this training process as well as in co-facilitating some meetings with the first author. Information on visual research ethics, that encompassed the importance of consent, confidentiality, and identification within visuals, was also discussed with the children.

Based in the recognition that "research can be a powerful tool for social change- and for maintaining the status quo" (Potts & Brown, 2015, p. 19) a key ethical decision made by the first author, in collaboration with committee members, in the proposal stage was that all videos created would be unidentifiable. For example, photos and videos of objects would be used to represent issues and people in different ways, and any faces of people would be de-identified through use of blurring. Disability within the Indian context has been linked to negative stereotypes, including, being considered ‘evil’, ‘of lower status’, or seen as a retribution for past and present sins (Anees 2014), which shape and contribute to situations of marginalization (Wolbring & Ghai, 2015), and the researchers sought to avoid further marginalization through the course of this project. Although there was the potential to blur out identifying visuals after filming, the first author wanted to support the children to use their creativity to capture visuals in an unidentifiable manner so the final film would be aesthetically pleasing. Given this, training encompassed key elements of how to capture video footage without having identifiable information and children were given the space to creatively do so. The training process was ongoing based on what children needed help with during specific parts of the video making process.

4.3.2.5 Video making through shared reflection and analysis

Following completion of initial training, children with disabilities met regularly as a group to discuss and engage in shared reflections surrounding the issues they had identified. During this period, children used cameras as tools to visualize their thoughts
related to the identified issues. Overall, this process involved cycles of discussions, capturing of video footage based on discussions, followed by viewing footage and further engaging in deeper shared reflections (see Table 6 for an overview of meetings and activities). This cyclic process of information gathering and shared reflections acted as a means for collaborative dialogic analysis, that included an analysis of everyday experiences as embedded within broader socio-political, cultural, and economic contexts (Farias et al., 2019). This dialogic approach is underpinned by Freire’s (1993) work on critical pedagogy that calls for an egalitarian process of shared dialogue among collectives experiencing injustices as means to explicate further understandings on the situatedness of the experiences of injustices and advance social action (Farias et al., 2019). Specifically, this dialogic process of analysis addressed the ‘primary text’, which included the media produced by participants (Gubrium & Harper, 2013), and was carried out with the children using the SHOWeD approach to analysis, which encompassed questions like, what do you see here? What is really happening here? How does this relate to our lives? Why does this problem, concern, or strength exist? What can we do about it? (Wang, Cash, & Powers, 2000).

Table 6. Overview of Meetings and Activities

<table>
<thead>
<tr>
<th>Group Meetings</th>
<th>Focus</th>
<th>Examples of Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5</td>
<td>Rapport building; getting familiar with the camera</td>
<td>Ice-breakers; games allowing self-exploration of working a camera; photo-elicitation</td>
</tr>
<tr>
<td>6-8</td>
<td>Focus on occupation; identifying issues; camera use; training on video capturing</td>
<td>Sticker activity with drawings on occupation; Post-it activities; participatory video games from the participatory video handbook (Lunch &amp; Lunch, 2006)</td>
</tr>
<tr>
<td>9-12</td>
<td>Storyboarding; prioritizing themes for video; visual ethics discussions; practical training on filmmaking process; training on manual camera functioning</td>
<td>Paper pencil tasks; role playing; simulation activities with cameras; discussions</td>
</tr>
<tr>
<td>13-18</td>
<td>Discussion on challenges faced at the personal level and occupations they enjoyed doing;</td>
<td>One-on-one discussions; sticker activity; guided walks; video elicitation; group discussions</td>
</tr>
</tbody>
</table>
video captures; shared reflections

19-22 Recap of the process; choosing pseudonyms; planning the different scenes and storyline

23-25 Capturing more videos; shared reflections; more discussions on the need for de-identification; shaping the narrative

26-28 Training on video editing

29-33 Re-recording of scripts; video capturing; collaborative editing

34-35 Shared reflections on solutions; video capturing; more editing

36-38 Wrapping up

Overall multiple methods were incorporated to facilitate discussions and shared reflections among this group. Many of these methods were chosen by children. For instance, guided walks to specific spots within their village were common as they wanted to capture videos related to their issues of concern and engage in deeper discussions and reflections based on what they saw in the physical environment. Role playing was another method that children used when they were engaged in learning the filmmaking process. They chose topics, decided on their roles (e.g., actors, producer, and videographer) and enacted different scenes about their topics (e.g., issues of teasing and bullying of children with disabilities). These role-playing sessions helped them further engage with the issues of concern and share some of their personal experiences with the group while also engaging in the process of filmmaking. Some methods were also initiated by facilitators. For instance, drawings on paper were used by the facilitators so children could visually represent the different scenes what they wanted to capture within their film. Photo and video elicitation were also used during the training period so children learned how to choose a topic, capture related visuals within their communities,
and then circle back as a larger group for discussions. Lastly, one-on-one discussions, in places chosen by the children, were used to enable children to share personal experiences when it was hard for them to do so in a larger group, especially during the initial days of the participatory filmmaking process. All these methods combined together helped to facilitate shared reflections.

All discussions were audio recorded and sections from these discussions were used to create the narratives for the final video. Children often chose not to re-record what they had previously said within the discussions and worked with the first-author to split the audio clips from their recordings and create their audio narratives. The first author listened to all meeting recordings multiple times and developed an overall story line from the children’s narratives, in a manner that had no repetition of information, which created a platform for the editing process. During editing, the children had the opportunity to further refine their storyline, and information was removed, added or moved around based on their preferences. Additionally, the first author had regular phone conversations with local film makers to support her learning about the filmmaking process, which she incorporated within this project.

All children were trained by the first author in the process of putting together different media to create a film (i.e., videos, voice overs, and music), that is, skills related to video editing using the iMovie software (version 10.1.6. Apple Inc. 2001-2017), which is a basic and user-friendly film editing software. Each of them had the opportunity to individually first create a short one-minute video as a practice video with the clips they had captured. The first author worked with each child individually, for about 2 hours, showing them how to use a laptop, how to open the different folders on the computer, and then how to use iMovie for the editing process. When working on iMovie, children made decisions with regard to what videos they wanted to use, background music, as well as filters for visuals. Overall, the children found the concept of filmmaking and editing very interesting as well as relatively easy on the iMovie software.

Later, these skills were utilized when making the final video. Based on their level of interest, children were involved in editing different pieces of the final video, such as,
trimming audio, dragging relevant video clips and trimming them, and editing colours. During the process of creating the video, there were also many discussions and reflections surrounding the dissemination process.

4.3.2.6 Dissemination of the short film

Once the short film was created, relevant stakeholders were identified by the children along with the first author to assist with dissemination. The dissemination strategies were developed considering both the principle of reciprocity, that is, circling and reporting back to the community who had been involved within this film making process (Smith, 2012), and the goal of enhancing awareness of the childrens’ experiences and identified areas for action amongst diverse stakeholders. The dissemination process was started by sharing the video with staff and students from the local collaborating institution. The staff members watching the video included doctors, nurses, social workers, occupational therapists, other health care professionals and occupational therapy students. In addition, the video was shown to parents and other family members from the community that the children invited. Children were present at both these meetings and answered questions that audience members had about the video.

In addition, the video was shared with local village leaders to sensitize them about the issues that the children had identified. To lessen the chance of retribution, children were not present for that dissemination meeting. This decision was made by the first author along with the social workers from the institution who were leading this meeting with the village leaders. There were five other disseminations by the first author within different departments and student bodies in the local institution to support identification of people interested in being a part of the action phase of this project. The children were not present for these disseminations as they were carried out during regular school hours. The children, however, decided that they wanted their video to be shared on social media to sensitize people from outside their community, and people within the community through indirect dissemination, to the issues that they had spoken about, and their parents supported this decision. Therefore, this video has also been disseminated online. As Mitchell, De Lange and Moletsane (2017) remind us “failure (on the part of researchers) to come up with a way for photos or other visual images and productions to reach
appropriate audiences is part of that silencing” (p. 8), which this process sought to challenge. Overall, various means for dissemination of the video were utilized and these dissemination processes acted as a starting point for mobilizing the action phase.

4.3.2.7 Wrapping up the participatory video making and dissemination phases

This PAR project was established on the ethic of reciprocity (Maiter, Simich, Jacobson, & Wise, 2008), where relationships based on trust formed the foundation for this work. In turn, it was important for the facilitators to have the time to wrap up the project and say goodbye to the children and their families, especially since the first author was traveling back to Canada to finish her PhD education. The dissemination process initiated the farewell process, but there were also additional days where the children requested the first author to meet them in the village, play games, and spend time chatting with them as a way of ending this process. The last few sessions worked as a reminder that this phase of the project was coming to an end. Specific activities were carried to facilitate the exiting process, such as, writing notes to one another, playing games for the last time that children enjoyed doing as a group, and visiting spots that were special for the children within their village.

4.3.3 Action phase

4.3.3.1 Proposing solutions

Children also proposed relevant solutions (see Figure 4), which ranged from creating programs for specific issues (e.g., tree planting program addressing deforestation); disseminating their short film on social media to sensitize people within and outside their community; collaborating with people in power within the village and the government; and creating other means of dissemination (e.g., books, posters, etc.).

4.3.3.2 Creation of action teams

The action phase was initiated during dissemination when local community stakeholders, on watching the film, had expressed interests in being involved in the action phase. This action phase is an ongoing, continuous phase that includes collaborations with
community stakeholders (e.g., village leaders, social workers in the institution, and community organizations, etc.) who have the capacity to mobilize action addressing the issues brought forth by the children. Once the video was disseminated among different groups within and outside of the institution, action teams were created encompassing individuals interested in working on each of the issues brought forward by the children, and action plans are presently being mobilized in different areas (e.g., the social workers have included issues of teasing and bullying within their school health education programs; the institution is working with the local health leaders on cleaning up specific areas within the village as well as in negotiating initiatives on tree planting along with a local forestry organization).

Figure 4. Proposed Actions by Children

4.4 Negotiating Contextual Features and Challenges within this Participatory Filmmaking Process

In this section, we share some technical and pragmatic challenges faced within this filmmaking process, as well as how we attempted to negotiate these challenges to align
with participatory and inclusive principles guiding the project. Certainly, challenges to research processes are contextually shaped and will vary in how they play out within each project, but these insights can support a critical, informed uptake of this methodology for participatory and inclusive research practices.

4.4.1 Technical elements of participatory filmmaking

Challenges were associated with the technical aspects for filmmaking. For instance, we dealt with limitations regarding type of equipment available for the filmmaking process, and questions regarding whether the methods commonly used within filmmaking processes were relevant within this context (e.g., storyboarding). As well, there were tensions when trying to navigate the balance between focusing on the quality of the final product and the filmmaking process.

4.4.1.1 Technological equipment

As noted previously, a few point and shoot digital cameras were borrowed from friends and family to use within this project. Most of these cameras had to be returned to their owners once the project was over. In turn, children had access to cameras only during group time, which minimized the time each child spent with the equipment. This could have potentially been a barrier in furthering their camera related skill development. In addition to limited access to cameras, the children had access to only one computer, which was the first author’s laptop. All editing needed to happen on this one computer.

This was the first time most of the children were using a laptop or even a computer. Therefore, we built in individual time for each child to learn how to use the laptop as well to receive training on the video editing process. Although all children were involved within the editing process, there was a limit to what could be done within one-two hour block a day, so each child did approximately 5-10 minutes of editing each day and handed over the different editing tasks to the first author. For children to contribute more within the editing process, they needed better access to a computer; however, that was not possible within the scope of this project. The first author met the entire group for about 1.5-2 hours in the evening, and by the time she got each one to individually work on the editing tasks in the one available laptop, only a few seconds/minutes of the movie got
edited per day. Moreover, children also got tired using the computer and concentrating for that long, as it was not an activity they were used to doing. Overall, this meant that being flexible regarding the timeline and number of meetings was essential to enable ongoing participation of the children.

Additionally, all instructions within the laptop were in English, which was not the first language for the children. To address this contextual challenge, the first author gave instructions using letters as the children were familiar with reading letters of the English language. For instance, if they had to open the folder called ‘pictures’ on the desktop, she would say open the folder starting with a ‘p’, but over time with practice they became familiar with process and knew the different icons or folders. At the same time, it is acknowledged that having a lack of funds to give each child personal access to a device for editing was a challenge that could have impacted the sense of children’s ownership within this process.

4.4.1.2 Creating voice-overs and editing

Within this cultural context, it is not common for children to share their feelings and emotions in public. However, after building rapport and creating a safe space for children to speak about issues they wanted changed, they shared their perspectives within group meetings, which were audio recorded. These audio recordings then created the narrative for their film, and the children were not as comfortable with re-recording the script of their narratives as they would have to re-engage with what they had said before about their struggles and challenges, which was emotionally taxing. Some of them did try re-recording bits and pieces of their narratives, but overall, they requested that the first author use recordings of what they had said previously in the group meetings as a narrative for their film.

Once the voice overs were split, they were used within the process of creating the video. This process was again uncomfortable as they had to listen to themselves and their emotional experiences of exclusion and marginalization over and over again while choosing relevant visuals and editing the video. This processing and re-processing of information during the editing was uncomfortable for the children, and some of them on
certain days had requested the first author, “why don’t you just do it?” Moreover, the first author also shares in her journal, “I was not comfortable with them being uncomfortable. In turn, I had to take over many aspects of the editing process”. Indeed, Sudbury (2016) reminds us that “it is in the edit where the filmmaker can exert a great measure of control. It is here where the narrative is created and it is the means by which filmmakers begin to supervise and direct their viewers’ experiences of reading and creating meaning from their films” (p. 225). With this in mind, there was a tension that the first author constantly faced, and she worked with the children as much as they could and wanted to within the editing process, but she also wanted to create that space where they could say no if they did not like the process or felt it to be too taxing on them.

4.4.1.3 Process versus product

Another tension faced by facilitators was related to navigating whether the created film had to be of professional quality versus valuing the process and accepting a non-professional output. The co-facilitator was a professional photographer who considered a good final output as essential, which the first author acknowledged. As such, representations of children through the film’s output, and feedback from the community, could have an impact on the children who created it. However, there were points where the facilitators had differences in what they were expecting as outcomes for this project.

The professional photographer, the third author, posed an important question related to expectations of this project: “have you ever thought of it from this perspective, that you are trying to teach them … an art that people take years of experience to master…. you try to bring in the same art, and teach it to kids in like one or two months and expect them to make a movie out of it, would you find that target to be a little hard to achieve?” The first author on the other hand sought to clarify that the focus needed to be on the process to support children in sharing perspectives on matters concerning them. Acknowledging these different points of view on the aspects of the filmmaking process, the first and third author engaged in regular dialogue and discussions after meetings (i.e., about what went well, what did not, and what were some challenges faced, and how could they make things better the next session, etc.). These shared reflections on the process played a central role in helping them understand where each of them was coming from as well as
in negotiating those differences, utilizing strengths, and working together towards a common goal, which acknowledged the means being as important as the end (Gubrium, Harper, & Otañez, 2015).

4.4.1.4 Storyboarding

The storyboarding activity, a process of planning the film’s story on paper (Lunch & Lunch, 2006) was challenging to execute within this context. When we introduced this activity, children were caught up in using the stationary that was given to them and attempting to make perfect drawings. Children had also started drawing things that they liked and coloring it, versus drawing or writing what they wanted to capture on their cameras. On the other hand, many children refused or found it hard to do tasks in a notebook and asked the facilitator to do it on their behalf with verbal instructions from them. This reluctance could be related to the links between this activity and their school related tasks, which seemed to have an emotional burden attached to it. It potentially links to their experiences of school exclusion as well as judgement by teachers, in turn, expecting their work on paper to be critiqued by the facilitators.

In trying to navigate this challenge, the facilitators did not use storyboarding again and minimally used notebooks within the process to guide the creation of the narrative, but rather used group discussions and shared reflections as a basis for the film’s narrative. Most decisions for specific footage to be captured were discussed and planned verbally followed by walking through the villages to spots where children wanted to capture their videos. Therefore, the filmmaking process did not progress in a linear fashion of a story leading to filming and then editing, but rather there were circles of discussions, filming, more discussions from watching video captures, then more filming, editing, and then circling back to more filming and so on. It was a complex, flexible, and open-ended process as the facilitators had to work with existing needs and interests of the children within the filmmaking process. Thus, the storyboarding activity was replaced by an oral approach to story development commonly used among collectives facing barriers related to literacies (Hill, 2010).
4.4.1.5 Barriers to collaborative analysis

Participatory digital and visual research aims to incorporate research participants in data analysis (Gubrium & Harper, 2013). Within this project, children were involved within the first round of dialogic analysis where topics were revisited by the facilitators to allow the group to engage in deeper discussion and shared reflections of issues, which then informed the narrative of the film created. Furthermore, this process of collaborative dialogic analysis also encompassed discussions that supported in-depth analysis of information from visuals. However, a second round of theoretical analysis, a central component of a PhD project, was carried out by the first author after she had left the field with no means of working with the children in this process. This theoretical analysis requires additional training for children as well as time, which is especially restricted in projects, such as this, carried out within the scope of thesis work.

4.4.2 Pragmatic challenges

Everyday challenges faced in the field, such as uncomfortable weather conditions and a lack of human resources, also influenced and shaped this participatory filmmaking process.

4.4.3 Uncomfortable weather conditions

This project was carried out during the peak summer months in one of the hottest places in the state. Although we had access to two rooms within the village for meetings, there was no fan within those rooms, and the children preferred meeting outdoors. The weather impacted the energy available and mood for both the children and the facilitators. This was especially problematic as our initial meeting times, during children’s summer vacation, was in the day time and sometimes the meetings took place until noon, which was the hottest time of the day. In turn, on some days, going out in the sun for a guided walk was not possible and children had to capture videos within the areas surrounding the meeting spots even if that was not their preference. Overall, the children always chose meeting spots that had shade and were relatively cooler when compared to the indoor locations, which made the meetings work well.
Furthermore, as the project progressed and the meetings transitioned into evening meetings once schools reopened, we entered into the monsoon season. There were days when the facilitators could not go regularly to the village due to heavy evening rains as the mode of transportation for facilitators was a two-wheeler motor bike or scooter. These abrupt changes in schedules affected agendas for the day as well as created irregularity in meetings with the children which acted as a barrier for making progress with the film.

### 4.4.4 Human resources in the field

This project was carried out as a part of the first author’s PhD work and raised questions about how collaboration can play out in the context of a dissertation, particularly in a context in which faculty and students are embedded in traditional hierarchical power relations. From the first author’s perspective, these power relations led to uncertainties regarding how much involvement was considered acceptable within the scope of a thesis project and posed a barrier in creating a shared sense of ownership that is key to strengthening sustainability of project related participatory goals and transformative agendas.

Additionally, there were a few challenges in terms of how professionals, the local co-investigators, were positioned within that community. The local co-investigators were health-care professionals from the institution serving this community, and when one of them visited the village with the first author to help co-facilitate the first meeting, the children implicitly felt like they needed to be quiet and respectful around the health care professional. Within this context, power differentials between adults and children are inherent, and children are taught at a young age about what actions are considered respectful and disrespectful. For instance, children questioning or challenging an adults’ point of view, or sitting when the adult is standing, are considered disrespectful.

To support the sharing and negotiation of power within this process, what seemed to work within this context and this project was to intentionally involve a co-facilitator, that is, the professional photographer, who was younger in age, and who was willing and able to sit down with the children on the ground and play games alongside them, which many adults or professionals within this context may not be able to or consider appropriate to
do. Moreover, having a co-facilitator who the children were comfortable working with and looked up to as an older brother rather than a teacher was important. The facilitators knew that power was shared when children addressed them as ‘akka’ and ‘anna’ meaning older sister and older brother rather than calling them their teacher, sir, or miss/ma’am.

4.5 Discussion

It is proposed, based on experiences and the outcomes from this project, that participatory filmmaking can be one approach to facilitate involvement of children with disabilities as active agents in research initiatives that guide community development. However, it is important to acknowledge that the process is not linear or replicable, but rather, one that embodies layers of complexities that need to be negotiated differently within different projects.

Although the feasibility and the need for flexibility in response to context and challenges of this process have been emphasized in this paper, a key question that this section seeks to discuss is: What might be some key factors to consider that would support the utilization of participatory filmmaking within inclusive research practices?

A key element that facilitated better involvement of children with disabilities as collaborators was the use of fun activities that not only engaged the children within this process, but also worked towards building reciprocity and trust among the group and challenging dominant power differentials between adults and children. Reciprocity is defined as “a technique for building relationship and avoiding exploitation of research participants” (Mockler, 2011, p. 164). Importantly, through reciprocity and authenticity “individuals and communities can become empowered to understand, produce knowledge and bring about active positive change in their own lives” (Bridges & McGee, 2001, p. 213). Through culturally relevant fun activities and games within the scope of this project, relationships among the group were established, which supported children in sharing their first-hand perspectives and being better connected with each other and in turn the process.
Participatory filmmaking, like other participatory methodologies, seeks to move away from objectivist or positivist forms of research that separate the researcher from the researched, acknowledging the centrality of the relationships between the researcher and community members (Parry, Johnson, & Stewart, 2013). This methodology is not just a technique but embraces relationality, where all methods used need to be rooted on the foundation of trust, respect, and genuineness (Kral, 2014). Within this participatory filmmaking project, in addition to building relationships with the children through fun activities, the facilitators actively worked to establish community relationships by meeting with parents of children with disabilities prior and after every group meeting to make sure parental requests related to meeting logistics were respected and addressed on a day to day basis. An ethic of reciprocity (Maiter et al., 2008) is especially important when working with collectives who have historically experienced unethical research relationships. If researchers carry out research processes in an objective manner, it can stand the chance for re-enacting historical oppression and unethical research practices (Potts & Brown, 2015). For instance, within this participatory filmmaking project, if the facilitators had not established a relationship with the children, the representation of children within the film or its consequences might not have mattered to them as much, which could have further perpetuated issues of marginalization that this project sough to address. Building relationships are essential and they require time, flexibility, trust, respect, and a keen interest in the work being done.

Moreover, although participatory filmmaking can create a platform for silenced voices to be heard and opens up possibilities for better social analysis of issues, it holds no guarantee for liberation (Tilleczek & Loebach, 2015). Within this project, children with disabilities identified issues that mattered to them as well as proposed numerous solutions, but it still requires a commitment from researchers and community stakeholders to actually mobilize the transformative agendas. It is indeed crucial for scholars who embark on this journey to embrace a moral responsibility to support or guide the enactment of action plans highlighted within the scope of their project. With the creation and dissemination of the film comes a new responsibility that mandates ‘more’, so the social transformation hoped for can actually be obtained. Moving into and engaging in this action phase will continue to require on-going flexibility in the process,
particular as the principal investigator is no longer situated in the study context. However, she continues partnership through virtual meetings with the stakeholders in the local collaborating institution for supporting the enactment of action plans.

4.6 Conclusion

In making transparent the methods used, challenges faced, adaptations, and strategies, within this participatory filmmaking process with children with disabilities, we do not intend that there is one correct way of approaching this methodology, but rather, our aim was to highlight that there are ways forward for utilizing this methodology for inclusive research practices. Children of all abilities need a space for their voices to be amplified, which participatory filmmaking has the potential to create. By utilizing this methodology, the heterogeneous nature of disability-related lived experiences can be shared and used as a means to guide social transformation.
4.7 References


Chapter 5

5 Navigating Ethical Tensions through Critical Reflexivity: A Participatory Filmmaking Project

5.1 Introduction

The United Nations Convention on the Rights of the Child (United Nations, 1989) recognizes and promotes children’s right to involvement in research as a means to express their views on matters affecting them (United Nations Children’s Fund, 2007). Aligned with this recognition, there has been an increasing uptake of participatory research practices with children to involve them as collaborators (Bradbury-Jones & Taylor, 2013). Indeed, participatory research is characterized by promises for equitable collaboration and social transformation (Benjamin-Thomas, Corrado, McGrath, Laliberte Rudman & Hand, 2018). Moreover, there has been an expansion of methodologies used within participatory research with children, which are posed as not only adaptable, engaging, fun, creative and innovative, but also as supporting collaboration by challenging traditional power differences between adult researchers and children (Benjamin-Thomas, Laliberte Rudman, Cameron, & Batorowicz, 2018; Young & Barett, 2000).

Irrespective of specific methodologies, challenges are often encountered when supporting children’s participation which are shaped by cultural, economic, and socio-political forces. When addressing ‘ethics in practice,’ the everyday ethical tensions faced when carrying out a research project (Guillemin & Gillam, 2004), attention is paid to the ongoing prioritization of human dignity (Graham, Powell, & Taylor, 2014). Challenges also encompass day to day pragmatic difficulties, such as restricted time, resource availability, and varied understandings of practices, that can lead to ethically important moments, “the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research” (Guillemin & Gillam, 2004, p. 262). More broadly, ethical tensions can encompass ethical uncertainty regarding whether a situation is a moral problem, ethical distress related to constraints on acting in ways viewed as right, and ethical dilemmas when faced with untenable alternatives (Kinsella, Park, Appiagyei, Chang, & Chow,
Within the field, researchers may constantly face ethical tensions which emerge and persist long after receipt of ethics board approval (Canosa, Graham, & Wilson, 2018). Ethical tensions are often related to power, positionality, beliefs, norms, fears, expectations, outcomes, and responsibilities. For instance, varied socio-cultural notions of a child’s position within society (Twum-Danso, 2009) or an adult researcher’s perceived responsibly to protect (Graham et al., 2014) or care (Phelan & Kinsella, 2013) for children during the research process can contribute to ethical tensions. To address such ethical tensions, researchers have called for ‘living ethical practice’ where “we put ourselves and our academic egos to one side and think instead of the wellbeing of those who are often vulnerable and lacking in power” (Groundwater-Smith, 2011, p. 209).

On-going critical reflexivity, defined as a “continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data but also to the researcher, participants, and the research context” (Guillemin & Gillam, 2004, p. 275), is a key means to address ‘ethics in practice’ (Guillemin & Gillam, 2004; Phelan & Kinsella, 2013). Such reflexive practice needs to extend beyond just the academic researchers to all collaborators or co-researchers. Mitchell and colleagues remind us, “if we engage in a continuous process of reflexivity, negotiated and re-negotiated with our participants, ethical relations within the research context are enhanced and the research process itself is democratized” (Mitchell, De Lange, & Moletsane, 2017, p. 14).

Engaging in reflexivity not only draws attention to ethical moments by addressing questions of ‘what’ and ‘why,’ but can propel engagement with the ‘now what’ through conscious considerations and actions responding to ethical tensions (Graham, Powell, & Truscott, 2016). This practice of reflexivity is particularly relevant when utilizing participatory methodologies that embody an ethical commitment for the democratization of the research process (Canosa et al., 2018) in working towards ideals of equitable collaboration and social transformation (Benjamin-Thomas, Corrado et al., 2018).

Phelan and Kinsella (2013) point out “discussing reflexivity in relation to ethics and research is one thing; however, enacting reflexivity in our everyday research practice is far more challenging, or shall we say, easier said than done” (p. 87). As a means to support scholars in enacting reflexivity for guiding living ethical practices, there have
been numerous calls for transparent accounts of ethical moments faced by scholars in the field, practices of reflexivity, and resulting decisions and actions (Graham et al., 2014).

Thus, we aim to present a detailed account of how we utilized a critical reflexive approach to document and navigate ethical tensions faced in carrying out a participatory action research project (PAR). We first provide a brief overview of the project and then discuss the range of experiences and critical reflections that reveal the numerous layers of ethical complexity involved in carrying out this participatory filmmaking process. Specifically, we explicate key ethical tensions within this kind of work and share how we employed reflexivity to navigate ‘ethics in practice.’

5.2 Project Overview: Participatory Filmmaking with Children with Disabilities

As a part of the first author’s PhD thesis, a PAR that utilized participatory filmmaking as a research methodology was carried out with six children with disabilities from a rural village in India (Benjamin-Thomas et al., under review). This project was enacted through a local institution’s community health department that provides health and development services in the area where this research was carried out. The children were aged 10-17 years and were identified by health care practitioners or their community members as having a disability, some of them formally diagnosed and some not formally diagnosed. The nature of underlying impairments included speech and hearing impairment, visual impairment, mild-moderate intellectual disabilities, hyperactivity, or past histories of psychiatric conditions. The first author was the lead researcher who conducted all meetings with children, and the third author, a photographer by profession, helped co-facilitate many of these meetings. All meetings with children were conducted in the local language (i.e., Tamil) as both facilitators were fluent in Tamil, and the recorded meetings were translated from Tamil to English by the first author with support from a retired teacher from a neighbouring local community. Reflexive dialogue sessions between the lead and co-facilitator were conducted in English. Further details about the phases of this project, pragmatic challenges, and key findings are described elsewhere (Benjamin-Thomas et al., under review).
5.3 Creation and Analysis of Reflexive Notes

As critical reflexivity is foundational to socially just research practices (Strega & Brown, 2015), the first author engaged in reflexivity from before the initiation of this project until after its completion as a means to address ethical issues and power relations within the research process. She maintained a reflexive journal to continually jot down and consider how her interests, positionality, and ideology influenced key decisions made within this research process and, in turn, shaped its outcomes.

She also engaged in dialogic\(^7\) shared reflexivity, a process when two or more people engage in reflexivity together through conversation, once every few meetings with her co-facilitator to collaboratively identify and address power related issues and challenges to enacting ideals of participatory research within the research process. The co-facilitator was a photographer whose role shifted from volunteer photography trainer to co-facilitator early in the project. Furthermore, the facilitators engaged in shared dialogic reflexivity with the child co-researchers throughout the participatory filmmaking process to identify challenges to participation, explore shared experiences, and address power differentials. In some instances, the visuals captured by children were used as supports to facilitate dialogic reflexivity with child co-researchers. An overview of the open-ended questions often discussed among facilitators as well as with child co-researchers are provided in Table 7. Through this continual reflexive process, the facilitators sought to embody cultural humility (Tervalon & Murray-Garcia, 1998) acknowledging differences in cultural values, beliefs, and practices, while working collaboratively with child co-researchers and various community stakeholders.

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\(^7\) Within the scope of this paper, the dialogical process referred to is rooted in Friere's (1993) critical pedagogy and its call to further understandings on the situatedness of experiences through an egalitarian approach to shared dialogue (Farias et al., 2019).
### Table 7. Guiding Questions that Supported Shared Reflexivity

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<td><strong>Shared Reflexivity: Facilitators</strong></td>
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<td>What went well today? What did not go well? What could we change for next</td>
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<td><strong>Shared Reflexivity: Child Co-Researchers</strong></td>
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<td>Did you like the activities today? Are there any activities</td>
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<td>you didn’t like today? Anything you would like us to change</td>
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<td>for tomorrow? Did you feel like you contributed a lot to this</td>
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<td>project and how? How could we have done this project better? If we were</td>
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<td>to re-do this next year, what would you like changed? What do you think</td>
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Overall, the reflexive notes included within this paper encompass the first author’s researcher journal as well as the transcribed (and translated) shared reflexivity with co-facilitator and child co-researchers. Drawing from these reflexive notes, this analysis seeks to exhibit transparency and honesty about the research process (Tracy, 2010) highlighting ethical tensions faced in working towards the PAR ideals of equitable collaboration and social transformation (Benjamin-Thomas, Corrado et al., 2018). These reflexive notes were independently coded by the first two authors to identify themes related to how ethical tensions were understood and negotiated (Miles, Huberman, & Saldaña, 2014). The identified themes were further refined through on-going dialogue between the first two authors. The themes encompass ethical tensions addressing: striving for participation; navigating authenticity and risks; navigating facilitator’s voice and
representation of children with disabilities; and facing limits to enacting immediate action. Within each theme, we first highlight challenges and tensions, then contextualize them within existing cultural practices, and end with sharing strategies used to manage ‘ethics in practice.’ We do not assert that these strategies necessarily represent the ‘right’ resolution of ethical tensions, but rather, we attempt to be transparent about how and why they unfolded and what we experienced as flowing from them. Throughout the following section, the term ‘facilitators’ is used to refer to the first author (Tanya, principal investigator) and the third author (Jeshuran, co-facilitator). Child co-researchers are identified using pseudonyms.

5.4 Critical Reflexivity: Navigating Ethically Important Moments in the Field

5.4.1 Striving for participation

‘Participation’ in research processes ideally refers to children being “allowed, enabled, and supported” to make decisions regarding their involvement, as well as in carrying out their tasks of interest (Hart, 2008, p. 24). Within this project, the facilitators worked to create a space for children to be co-researchers and direct various aspects of the research process. For instance, children made everyday decisions regarding meeting details, such as, meeting location and time and the type of snacks they wanted. As well as making the decision to create a film as a group rather than as individuals, the children decided upon topics and content for the film (Benjamin-Thomas et al., under review). At the same time, however, there were numerous ongoing challenges to participation that presented as ethical moments within the research process. In striving for participation of children within this research process, the ethical challenges encompassed barriers related to having a closed group of children with disabilities, challenges with having a mixed group of children with and without disabilities, barriers to addressing the inclusive needs of children with disabilities, the varying ages of children within our group, and issues related to resistance and mistrust from children and community members.
5.4.1.1 Having a closed group of children with disabilities

This project sought to work with a closed group of children with disabilities because it sought to listen to the first-hand perspectives of their everyday experiences as a means to address change. Freire (1993) reminds us that the first step towards any social transformation is the unveiling of oppression by people experiencing such situations of oppression. However, other children without disabilities from the community wanted to be involved in project activities. For instance, the first meeting with our group was in a closed room, and many other children were peeping into the room through the one broken window and were constantly asking the facilitators if they could join the project. These requests happened everyday throughout the course of the project. This was likely connected to this project being initiated during their summer vacation, when all children were out of school, walking around in the village and playing games when their parents were at work. Moreover, most children were seeing cameras for the first time and genuinely wanted to learn how to use them. It also appeared that they were excited to see two outsiders visiting their village on a bullet-motorbike or scooter every day and wanted to be part of this novel event happening within their village. Moreover, members within this community practiced a collectivist way of life, and children with disabilities wanted their friends with them, or their parents wanted siblings to accompany them for safety reasons.

Reflexive notes from dialogue sessions between the facilitators pointed to a tension between wanting to be inclusive of all children to respect the collectivist way of life and the requests of children with disabilities and their parents, and concerns regarding whether the inclusion of children without disabilities would constrain the space for children with disabilities to express their viewpoints:

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8 The positioning of children within the two groups ‘children with disabilities’ and ‘children without disabilities’ is only for clarity purposes, and we acknowledge that both these groups cannot be viewed as homogenous and that the children within these groups may have embodied a range of experiences and responses.
Tanya: I think, having the other kids can sometimes change the dynamics. For instance, Shivam was initially so enthusiastic about recycling and garbage sorting, but when his friends joined in, he took a back seat and he was like “let’s go to the shop.” I feel like his passion really reduced for the issue after they joined in, so I am not sure if they always put him down, or I don’t know what...

Jeshuran: I feel, he feels a little conscious when too many people are around him.

Tanya: So, I don’t know how we can keep sending children out, as they keep coming in, and these kids also want them, but we have to try I think.

Jeshuran: But ya, that is something we need to work on somehow, either we learn how to manage with them and continue to do it, or we, as I said in the beginning, need to have an attention diversion for them.

(Facilitators’ Shared Dialogic Reflexivity)

In some instances, even adults from the local community wanted to step into the sessions and listen and contribute to what was going on, and we needed to embrace flexibility and cultural humility while navigating how the presence of such adults could also have constraining, and sometimes potentially damaging, effects:

Jeshuran: Not quite sure what it was, but it was like yesterday. So discussion time was also less, and we had a lot of outsiders peeping in and watching, like Sanjith’s mother was there for a while. He wasn’t dancing because his mother was there, and his mother kept saying “he will dance, he will dance.” Then the old man, that issue happened. Then there were a few people who came in and asked what was happening, and people had to say that we are doing social work, and all this commotion was happening when this was going on. We need a place where the kids are more focused on what is happening, and that is like the biggest challenge.

Tanya: Ya, even I feel that there are a lot of outsiders intruding, adults interacting, and the Shivam issue which happened, I was really upset by the fact
that the old man called him ‘mental’ or ‘acting mental’ and Shivam crying and everyone being upset and all those things... Everyone wants to speak for them, it’s like the whole community wants to speak for them. Sister, mother, father, neighbors, it’s like, we need to find a space that will help them speak out.

(Facilitators’ Shared Dialogic Reflexivity)

To work within existing cultural collectivist practices, we involved children without disabilities partially during every session. For instance, to deal with some children yelling from the outside and having conversations with children inside during the first meeting, we decided to involve the children from the outside within the rapport building activities planned that day. Once all children were involved, everyone got comfortable. Within those activities, children with disabilities were intentionally named as team leaders, which provided a good way to start building rapport within the small group as well as the extended community.

As the sessions continued, we created a pattern where we had a large group of children with and without disabilities for ice breaker games in every session. Once these games were over, we split into a smaller group and worked with the children with disabilities alone in the participatory filmmaking process. The other children often were around in the area (e.g., playing on the other side of the fields), and on some days we circled back as a larger group and wrapped up the day’s work with large group games and snacks. However, given parents’ requests, siblings of children with disabilities were often present within the sessions acting as a means of support. We communicated with the siblings about the objectives of the project and reminded them that we wanted to listen to the first-hand perspectives of children within our group, and most times the siblings were very supportive within the group process. To address the interruption of adults, children often decided to change locations during meetings so adult interruption was minimal.

5.4.1.2 Challenges with having a mixed group

The involvement of children without disabilities came with certain tensions, such as them calling children with disabilities by their impairments versus their names. For example,
during group introductions when it was Velu’s turn to share his name, other children yelled out “oomai,” meaning deaf and dumb. They made derogatory sounds in imitation of Velu’s voice when he attempted to speak, like “ba ba ba” and “mmm, mmm,” and the facilitators had to make an ethical decision to stop the meeting and share with the other children that what they were doing was hurtful. Velu, however, always gestured to the facilitators non-verbally to include the same friends who made fun of him within the group, by communicating that he liked them very much. These moments were a reflection of the day to day experiences of children with disabilities within that context, which the children came to speak about within their participatory film. Reflexive notes from the first author’s journal highlights some of these challenges:

_Tanya: When carrying out activities with cameras, children without disabilities tended to snatch away the camera from children with disabilities. I heard them saying that “he does not know anything” or “I can take a better picture than him.” These subtle discriminations of children with disabilities by children without disabilities were observed even among this group of children._

_(Researcher Journal)_

Moreover, children without disabilities were sometimes sources of distraction who attempted to insert themselves within group activities they were not invited to, which significantly de-railed the progress of our meetings on certain days. For instance, children without disabilities often followed the group to different locations and kept chatting with the children from the group and asking questions to the facilitators regarding their involvement in the activities for the day.

To respond to tensions arising from negative comments and behaviors related to disability, we often inserted a learning component into the large group game. Such components included aspects of simulation addressing the challenges faced due to impairments. For instance, all children had the chance to experience what challenges to communication with a hearing impairment felt like through playing a communication game using headphones with white noise in the background (Benjamin-Thomas et al., under review). Additionally, as facilitators, we established ground rules to deal with
teasing behaviours. These sessions supported children in understanding what was offensive, as some of them started identifying these behaviors in subsequent sessions and started addressing these issues among themselves. In terms of distraction, we had to keep moving spaces when working with the smaller group or had to request the other children to play a game in another spot and come back after a specific time frame for snacks. These shared rules helped ensure that we had some time as a small group but also respected their cultural ethic of collective practices.

5.4.1.3 Inclusive needs of children with disabilities

The children we collaborated with in this project were identified by health care practitioners and/or community members as having disabilities. Given a lack of resources combined with socio-politically shaped barriers, such as stigma associated with disability, it was a challenge to accommodate for their impairment specific needs. This sometimes hindered their full participation within this project. One such example was the challenge we faced when trying to create spaces for optimal participation for Velu who had a speech and hearing impairment. We could only communicate with him through actions and lip reading, which worked well for discussions encompassing ‘yes’ or ‘no’ questions or ‘what’ questions, such as, “what was the photo you captured today?” However, when we needed to engage in deeper discussions encompassing ‘why’ questions, it was hard to effectively communicate with him. Sign language was not an available option, as neither he nor the facilitators were trained in sign language. Efforts to use written communication also did not seem to work, as he kept copying everything that was written on paper rather than reading and responding to written communication. Throughout the process, the facilitators engaged in dialogue regarding strategies to optimize communication with Velu:

Tanya: It is hard, he cannot hear or speak. We want to include him, but at the same time we need to keep communicating with him on the side, and we are not sure if we are doing the right thing.

Jeshuran: I think we have to train and equip ourselves to simultaneously do it. If you are talking, I automatically have to tap him and make him look and try to act
out whatever your talking, and if I am picking up something and talking, you have
to get his attention.

(Facilitators’ Shared Dialogic Reflexivity)

Furthermore, we later realized that he had a hearing aid, but he refused to wear it. His mother informed us that he did not wear the hearing aid because other children made fun of it, and also because he and his parents were worried it might get lost as the other children often threw it around. It took us time to convince him to bring the hearing aid to meetings, but even when he brought it, he chose to have it in his pocket. To address this communication barrier, we tried different communication strategies such as including Velu’s sister to help with communication in addition to using written forms of communication. We then attempted to brief him about each day’s agenda by meeting him at his house prior to the meeting, where he would be comfortable wearing the hearing aid, so he would be in a better position to participate within the group. Unfortunately, we, as well as his mother, came to realize that one of his hearing aids was not working and it was too expensive for his parents to get it repaired or replaced at that point in time. Although we tried our best to be flexible and used visuals and other communication strategies, it was still hard to facilitate his full participation within this research process. He was present for most meetings, and participated in capturing videos, however, it was indeed a challenge to engage him within the shared dialogue and reflection processes.

In another example, we worked with two siblings, Arun and Kumaran, both diagnosed with intellectual disabilities. Due to financial difficulties within their family, they were admitted into a hostel for children with disabilities, where they stayed through the year and visited home once a year for a two-week period. We had the chance to work with them during these two-weeks, but it was hard for us to bring them to participate with the larger group of children who were also from the same village, even just for games. The brothers repeatedly articulated, “my teacher would hit me, if I play.” Moreover, their attention span seemed limited, which could be due to a lack of exposure to activities within their hostel. These experiences in their hostel were indeed a barrier to their participation within this project, but additionally, listening to these experiences
positioned the facilitators in an ethical tension in trying to explicate the issues of isolation, lack of occupation, and injustices faced within their hostel:

Tanya: *What they have been exposed to is very little. They have never seen a camera before or even worked with anything. They have not been allowed to do anything within their hostel. It is going to be so hard to facilitate their participation, as they are not allowed to do anything within their institution, and here they are given the space to do what they want, like they are even scared to play a game!*

Jeshuran: *Ya, they were like “my teacher will hit me if we play.” I was trying to teach him about the camera, showing him pictures and stuff, and he was like “no, the headmaster will hit me.” I don’t know if it is the medical condition in which they don’t realize that the headmaster is no longer there, or is the fear so much that they have this continuous paranoia?*

Tanya: *I think it’s the fear, as they are there the whole year, and they come home only for a few days a year. They are apparently locked in the building the whole year with other children with severe disabilities. Like what do you think could happen. It would definitely affect them.*

*(Facilitators’ Shared Dialogic Reflexivity)*

When working with Arun and Kumaran, we tried to be as flexible as we could, and met with them as a separate group, along with their sister, by their house which they preferred. We started with rapport building, and did activities that they liked (e.g., walks). To accommodate for their short attention span, our conversations were alongside activities that involved physical movement, like hiking with them to their favorite spot on the hill where they lived. Over time, we were able to establish good rapport, but by the time relationships were established, they had to return to their hostel; and although they learned how to use cameras and capture videos, they were not involved in the filmmaking process alongside the other group of children. Moreover, the many unknowns about their experiences within the hostel were discussed with their parents, who expressed that their
children were in a better position in the hostel as they received three meals a day which was not possible at home given their financial situation.

5.4.1.4 Varying ages of children

The ages of children who created the film, that is excluding the two brothers who resided in a hostel, ranged from 10 to 14 years. Initially, it felt like the older children (aged 14) were contributing more than the younger children (aged 10-11 years) within group discussions and tasks. Specifically, Karthi (aged 14) seemed to be more involved within the discussions than the other children. We wondered if the relative lack of participation of the younger children was related to their assumption, based on their experiences in school, that they would be judged for their actions; or if they assumed that there was only one way of doing things and did not want to expand on ideas already presented by Karthi. In turn, it seemed like it was easier for the younger children to follow the lead of Karthi, and it was hard to get them engaging in deep conversations, which was a central piece within the participatory filmmaking process. To address this challenge, we debated on whether to split the groups based on age:

*Tanya:* You were saying that working with the age group of Karthi and his sibling, the 14 year olds, was much easier when compared to the others who were about 10-11 years?

*Jeshuran:* Ya, as the 10-11 age group may enjoy the final output of it, maybe when we are shooting it, they may jump and act and stuff but the whole aspect of teaching them how to use equipment and guiding them on how to go about shooting.. they feel a little.. they find it a little dry. Whereas the older age group (14 years) is curious to learn, and fancy how it blurs and unblurs and things like that. With the smaller age group kids, I find the whole interest aspect a little lacking, or maybe it will pick up once we start shooting and stuff like that. The thing is with pictures it’s very easy to.. we can just capture it.. just like throw it on to a computer and do some minor edits, it will look fantastic. In videos, however, they are not going to see the output of it till they finish everything. So they need to constantly be motivated towards finishing that final output. They are not going to
get everyday satisfactory results like how you would get with pictures. That is something we need to consider and plan it accordingly.

(Facilitators’ Shared Dialogic Reflexivity)

To address this challenge, we also discussed the idea of providing more structure to the process, such as narrowing down to specific topics and delineating roles of various children, so everyone had the chance to contribute. However, we were also worried that too much imposed structure would constrain the participatory nature of the project. We worked to be patient and give children their time and space and motivate them to open up whenever they were comfortable and ready. Despite feeling time pressures, we committed to not rushing our agendas or pushing the meetings forward to maintain our timeline. As time progressed, when the children got to know each other better and were comfortable with each other, we found that both the younger and older children slowly started engaging in deeper conversations and contributed to the meetings meaningfully. For instance, one day (after a few weeks into the process) the children took the facilitators to a new location, the paddy fields, which was away from their normal location in the busy part of the village. In this new quiet location, they suddenly opened up about many different issues they wanted to address and these conversations were rich. Their discussions also related to each other’s experiences, highlighting how certain issues were a shared concern. The participatory process took a lot longer than expected. Some days in the village were only games as the children were not in the mood to have a discussion, which had to be accommodated for within the process. There were also other days that were mostly discussions and video making with very little play. This helped us, the facilitators, realize through shared reflexivity and self-reflexivity, that it was good to respect the pace of the children and it propelled us to consciously work towards being patient and flexible:

Jeshuran: I don’t know, today suddenly the kids seemed to be opening up more with the issues amongst themselves. Today for a change, each of them were like connecting themselves to each other within the group unlike the other times where it was always Sanjith and sibling were separate, and Karthi and sibling were
separate, and Shivam was separate. Today, they somehow landed on similar lines, similar issues and similar topics and they all spoke. That was something different today compared to all the days that we have been doing this. I think us playing with the kids did break more ice between us and the kids. They feel more like we are not just there to bore them with talks and recordings and pictures and stuff. I think it was actually good that today we went and played even though we sort of wasted a lot of time and didn’t do much with regard to the videos.

(Facilitators’ Shared Dialogic Reflexivity)

Tanya: I realized that when I had a structured plan and kept working on my tasks as opposed to just soaking in the temperament of the children and their interests for the day, it often made children disinterested. On the other hand, when I spoke to children and shared what is left within the process, and then gave them the space to decide the tasks for the day, it was a lot more fun, both for them and for me.

(Researcher Journal)

5.4.1.5 Resistance and mistrust

Although the participation of children developed gradually over time, there were times of resistance to their participation within the project, including resistance from parents, children themselves, and other community stakeholders. This resistance was often situated in broader socio-cultural forces within the community, such as stigma associated with disability, issues related to the safety of children, and other beliefs and practices. First, disability within this context has been associated with stigmatizing discourses, and in turn, there was stigma associated with children joining this project. A few children who were identified as having a disability, by their teachers and the local community health aide, were not involved in this project as their parents did not want to identify their child as having any form of ‘disability.’

Additionally, during the time this project was carried out, there were issues related to child trafficking within the neighbouring communities, and these reports were constantly
being shared on social media. Specifically, there were stories of outsiders visiting the village and kidnapping children by luring them with snacks, which had created a sense of fear within this community. During the first few weeks of initiating this project, a few parents seemed very cautious and did not send their children to activities in locations that were a little away from their homes even though they were within the same village. They preferred having them within eyesight.

In other instances, parental beliefs about certain activities and certain places prevented them from sending their children to meetings on specific days. For example, some parents did not like children climbing trees or walking through the fields due to the presence of venomous snakes; or were uncomfortable with their children meeting close to a particular well as they had mentioned that certain spaces including that well had ghosts. Additionally, some days and times, informed by their religious beliefs and practices, were considered as ‘not a good time’ by parents. For instance, when one of the children in our group fell off a tree one morning when he was picking a fruit, his dad felt like that was ‘not a good time’ for him to leave the house and take part in project activities.

Information such as this was communicated to us on an ongoing basis, and we worked to be responsive to adapting sessions based on these parental requests.

Additionally, mistrust, although minimally, was seen among children involved. For instance, Velu stopped attending our meetings regularly and we later found out that his mother had told him about child trafficking, which seemed to reduce his involvement in the project:

_Tanya: I am not sure why Velu suddenly seemed disinterested. This was actually after the day his mother had heard about child trafficking. His mother had told him not to accept snacks from strangers and that they will take him away. So he stopped coming regularly after, and his mother said probably that could be the reason as he was suddenly scared. She said that she didn’t think he would get this scared._

(Researcher Journal)
Mistrust was also seen among community members. At times, we, the facilitators, were approached by community members who asked questions about who we were and what we were doing within their community, which we interpreted as efforts to ensure everything was safe. Additionally, it was challenging to get permission from government schools to capture the school scenes that were a part of the film’s narrative, and school teachers seemed wary about the media even when it was communicated that no identifying details would be seen within the video.

To address these challenges, building of relationships was important, and over time, parents and community members gained trust and were willing for their children to be a part of this project. To establish trust and make sure that the parents felt safe about their child’s involvement, we visited the houses every day at the start of the meeting to inform the household that the meeting was starting, as well as ended the meeting by visiting each household to share that the meeting was over. We also made accommodations with meeting locations and snacks provided. For instance, if parents wanted the meeting close to their house on a specific day or did not want certain snacks (e.g., parents did not want children to drink juice on rainy days as it was seen as contributing to a cold), their requests were acknowledged and addressed on a day to day basis. Moreover, relationships established with the children over time had created a safe space for their involvement and enjoyment. As seen in the following excerpt, the children expressed enjoying the process and wanted the facilitators to spend more time with them and do more activities with them:

*Tanya:* What did you like the most in the last 6 months of this project?

*Karthi & Shivam:* Everything!! We liked everything!!

*Jeshuran:* Tell us one thing.

*Karthi:* I don’t know how to choose, I liked everything. I like being here now.

*Sanjith:* I liked using the camera.

*Shivam:* I liked doing editing a lot.
Sanjith: I liked you teaching us how to use the camera. I liked you coming to our village.

(Shared Dialogic Reflexivity with Children)

To address resistance from school authorities, the group had to adapt the process in terms of working with the space available and capturing school-related video scenes within community spaces outside of a school environment. Although one school eventually granted permission for videos to be captured within their premises, only one child from our group was available that day to do the video capture during school hours. Therefore, many of our school scenes were captured within their village outside of a school environment. Moreover, once the community members heard that this project was carried out in partnership with the local institution, many of their concerns and questions about us being in their village were clarified.

5.4.2 Navigating authenticity and risks

There were ethical tensions related to the authenticity of stories shared, and how the sharing of truth could have consequences for the safety of children.

5.4.2.1 Authentic voice

During the process of children identifying and prioritizing issues, we were hoping to have children bring forward challenges they were facing within their community related to having impairments. However, the most common issues initially brought forward were community issues, namely, garbage accumulation and deforestation, which persisted for weeks as a foci for discussion. It was certainly difficult to elicit discussions about challenges that each of them were facing at an individual level, as they kept speaking about community issues they wanted changed. We, the facilitators, were constantly trying to understand whether these issues were something that the children perceived as important in their lives, or if they were issues that were surfacing because they were taught about them in schools, or if it had to do with the location where we were meeting (i.e., right in front of the garbage sorting area). A tension within us, the facilitators, as highlighted within our reflexive notes, was trying to interpret if the issues brought
forward were something that the children really cared about, as it challenged many of our unconscious assumptions and expectations about what we thought were relevant topics of discussion:

Tanya: I think another thing we’d have to think about is that the garbage topic is recurrent. I don’t know if it is the location where we are meeting in, or if it really is an issue of interest.

Jeshuran: I feel that is all they are trained in school to talk about. Whenever people from environmental studies or social studies come and speak about what change we can bring about, I am sure that the teachers feed it into them ‘garbage disposal, garbage disposal’. So, it is like an easy door for them to like provide as an answer whenever they are faced with questions.

Tanya: But they do know a lot to say about that. I am not sure, I don’t want to stop them from speaking all those things, but at the same time we need to do alternate brain storming. Even in terms of photography, we are sitting right there where the garbage sorting happens. So they just go out, click pictures of garbage and then come back and speak about garbage. So maybe we should have the meeting somewhere else, like go to locations where people play games ...

(Facilitators’ Shared Dialogic Reflexivity)

As time progressed, and we had more discussions, by presenting questions that intentionally facilitated children in speaking about challenges faced at an individual and community level, and we heard about other issues children faced on a day to day basis (i.e., marginalization within schools and issues related to teasing and bullying). However, we also learned that the children were indeed concerned about addressing community issues (i.e., garbage, tree cutting). These issues kept recurring even after meeting spots were changed. Moreover, the lived realities of these community issues were brought to light when the children took us to different spots within their village for capturing videos. There was so much truth to these issues and how they were a burden for them and their communities. As Kellett (2011) reminds us, when research interests emanate from
children, and their understandings of their worlds and subcultures, no adult will be able to bring out the same richness of this knowledge. In turn, these experiences challenged us to think through, reflect, and expand the understandings and doubts we had about the process.

5.4.2.2 Considering the risks of sharing truth

Within participatory filmmaking processes, participants are encouraged to express their innermost thoughts and their experiences of oppression, which places ethical concerns at the heart of this process (Sudbury, 2016). Certainly, there were ethical tensions related to the consequences of sharing ‘truth’ when it encompassed things not typically permissible to say, and its potential to affect the safety of children involved. The raw messages that children shared included stories that implied their neglect and marginalization within schools, as well as other community and family tensions.

In participating in these discussions, we wrestled with a few questions with regard to how much ‘truth’ could be revealed? Should the film’s narrative be polished to make it seem more positive? Would that be moving away from the ‘truth’? We had to constantly navigate these tensions through shared reflexivity:

_Tanya: When we started this project, we wanted all children to be from one community, because we wanted the community to know what issues that the children are facing and that the community could address change, and that is why we didn’t want children from different villages. But now, when I am thinking back, everyone in this community might know who these children are who are making the videos. And when children are speaking about their real experiences of school exclusion…there are only like 3-4 teachers in the school. Everyone knows who the teachers are and everyone knows who these children are. So now, if we actually show this video back to the teachers, it is going to, I mean how much ever we try and change the film’s narrative, the identity can be revealed, because it is such a small and close knit community where everyone knows everyone._
Jeshuran: The way you frame this film’s narrative should be done in a more polished way, but that might dilute the content.

Tanya: Or maybe we would have to add an ending to it? Like a positive note to the film’s narrative, maybe like they were included later, but then it is not true. It is an issue of exclusion, why would we change it to inclusion? That is a key tension that I am facing. How do you think we could address this? What can we do or not do?

Jeshuran: There is no other easy way to it. You will have to go ahead with it and show it. Putting a positive message at the end of it, in one way will show like, we are actually trying to console the teachers or parents, it’s like we are trying to bandage the injury after causing it. I would suggest that you rather have the content done and let it be. I don’t think it’s going to be such serious consequences for the children and stuff. Or the other alternative is not show it in this village and only use it elsewhere, but that will be no purpose to your entire project.

(Facilitators’ Shared Dialogic Reflexivity)

Indeed, there were no easy answers, but Kellett (2011) reminds us, “as with all initiatives that involve children, safeguarding and protecting them has to be a top priority” (p. 213). Moreover, the first author, when listening to the meeting recordings to create a base audio-narrative for the film, was cautious so that no personal and identifying issues were included in the film (e.g., names of people, locations, as well as other identifiable details with regard family issues or schooling). This tension was addressed through discussions among facilitators and child co-researchers, during the filmmaking process, about what could be shared and could not be shared in the film, as well as where the film could be disseminated after its creation. Specifically, the facilitators and children reflected on whether their parents would get angry about seeing issues of substance abuse in families depicted as a problem; and how school teachers might react:

Karthi: if we show it to the teachers, they can say, “these kids are here just to blame us and complain about us” they can also fight saying “why did you make
us look so bad? And they may not include us in school...and also say “go join another school.”

(Shared Dialogic Reflexivity with Children)

After a few discussions, there were some details removed when creating the film, and the children and facilitators collaboratively decided that it was safe for the community in-person dissemination to happen only among close and extended family members of the children and other neighbors they wanted to invite, and not a direct dissemination among teachers. Moreover, the first author also stayed back in India for a few extra weeks after the dissemination just to make sure that the community dissemination went well and to monitor potential consequences for the children involved from the screening of the film.

5.4.3 Navigating facilitator’s voice and the representation of children with disabilities

Balancing the facilitator’s voice with the voices of children within the final film had to be navigated, along with issues of representation of children within the film as ‘disability’ was an identity attributed to children by community members but not an identity that children themselves embraced.

5.4.3.1 Navigating the position of the facilitator’s voice in the video

As the short film was produced and disseminated, its structure changed to include an introduction narrated by the first author, serving to contextualize the film and the process used to create it. This introduction by the first author was not included during the initial community dissemination, however, the first author was physically present to contextualize the work. Many viewers of the film suggested that it would be good for the first author to add her narrative about the process of making the video to contextualize the film and allow it to stand on its own. The first author then circled back to the children and discussed the idea of adding her narrative about the process. They agreed eagerly as they had wanted her to be in the video with them from the beginning.

The first author did not foresee including her voice in the film as she was wary of power differentials and did not want her voice standing out within the video created by the
children. This was because, “as facilitators or researchers we may inadvertently or inadvertently play a role in determining which stories get told” (Mitchell et al., 2017, p. 13). She wrestled with whether including her voice would portray the video as created by her rather than as a collaborative project with children. Moreover, there were tensions regarding whether her voice would dominate the video more than the voices of the children. However, when the children and parents requested that the film be shared online, it made sense for the contextual information about the process to be added to the film. After much reflection regarding how she could work with this feedback and not distance herself from the process, she circled back with the children who collaboratively captured footage about the process of creating the film.

5.4.3.2 Representation of identity

None of the children within this project identified themselves as having a ‘disability.’ They expressed how the community did not accommodate for their additional needs, but never did they identify themselves as having a ‘disability’ or as ‘special.’ They always situated their issues of teasing and bullying within the larger contextual issues of discrimination and violence seen among all children within their community, whether children were tall, dark, short, fair, as all of them experienced teasing and bullying. Some questions we wrestled with were: Do the viewers of the film need to know that the children involved were identified as having a disability and what kind of impairment? Would that affect the children in any way as they did not identify themselves as having a ‘disability,’ a construct not seen very positively within their community? Viewers of the film, after initial dissemination, had suggested that the film would benefit from making more explicit that it was carried out by children with disabilities for the message to be more powerful, particularly in challenging negative stereotypes related to inability. These suggestions created a dilemma regarding what was important, did we want the film to be more powerful? Would that be changing the narrative shared by children? Would the children feel different? The first author then had a conversation with the children and discussed whether they were comfortable with the first author sharing about their impairments in the introduction of the film, the children agreed to it, but even then, using the word ‘disability’ was not something the first author felt comfortable with. The first
author also wrestled with what words were appropriate, would it be ‘children with disabilities’ or ‘special needs’ or ‘additional needs’? This tension related to the identity of children and terminology use is something that is continually being reflected on by the first author, and after much thought, what was included in the film’s introduction was that this project was carried out with children ‘identified by their community as having special needs.’

5.4.4 Facing limits to enacting immediate actions

The first author went into this project hoping for social transformation, which is consistent with critical research values, however, during the process, relationships were established with the children who presented with various immediate needs. The facilitators realized that there were limits to their abilities as researchers to act in addressing immediate change for the children involved within the project.

Most children within the group had basic needs that were not being met, such as housing, electricity, schooling, lack of assistive devices, or adequate food. For instance, many children had no access to footwear, and during meetings, they would use pins to remove numerous thorns from their feet. Within our role as researchers, we wrestled with the boundaries on our abilities to immediately address these basic needs given our current purpose in the community. As facilitators we were not sure how to respond to the requests made by the children on a regular basis to get them footwear. It was also challenging for us to just watch them struggle when they were getting the thorns out of their feet during meetings. After a certain point in time and having reflected on it, it felt right to acknowledge their request and get them footwear from a local store at the end of the project. However, some of their requests, such as a request made by parents of the two siblings involved in this project to help them build a hut, were something that we were not in a position to do. They had lost their thatched hut due to a fire accident a few years ago, and their family was now living in a small tent made of sticks with no electricity or basic resources. To address requests such as these, we regularly forwarded the needs presented to us to the social workers in the collaborating institution. The institution, in turn, followed up and has been addressing some of these needs (e.g., providing free assessments, assistive devices, etc.).
Furthermore, we acknowledge that issues related to occupations, the focus of our study, were central concerns in the childrens’ lives. However, at times, we the facilitators felt a tension in terms of whether it made sense for the project to focus on occupational participation given the struggle for more immediate needs. We struggled with not being able to immediately ‘fix’ the issues for each of the individual children, but rather focusing on raising awareness of the collective issues and mobilizing forms of social action that did not provide quick fixes for the children we worked with. For instance, one of our group members had stopped going to school a few years ago, and within the scope of our conversations he had shared that he wanted an education but did not want to go to school again. Another child was on the verge of being dismissed from school because of his performance, which his parents kept telling us about. All of these children were talented and excelled within the scope of this work, but there was nothing concrete that could be done in terms of their individual educational needs. It created a sense of sadness knowing that their work has the potential to stir community change, but this change may not address their needs at this point in time. As such, the emotional burden associated with carrying out a PAR has been highlighted as complex, and as spreading across all members of the research team (Klocker, 2015), which is reflected in the notes from the first author’s journal:

_Tanya: The more time I spend with the children and their families within their community, the more burdened I feel. I listen, identify, and realize the different needs of each child, they are not needs that are difficult to meet, however, me not being in a position to meet those needs really hurts me and leaves me immensely burdened._

(Researcher Journal)

5.5 Ways Forwards in Enacting Researcher Reflexivity

This paper has made apparent the need for, and potential of, critical reflexivity in addressing ethical tensions within participatory and transformative forms of research. The process of engaging in reflexivity allows researchers to exhibit transparency, sincerity, and in turn, integrity as a means for guiding ethical research practices (Appleton, 2011;
Guillemin & Gillam, 2004, p. 262). Within the scope of this participatory filmmaking project, individual as well as shared dialogic reflexivity supported facilitators as well as children in thinking through and negotiating ethics in practice, that is, the complex ethical tensions faced when carrying out this project in the field.

In supporting the call to become a reflexive researcher (Phelan & Kinsella, 2013), we highlighted a few different ways researchers can engage in reflexivity. This is not an exhaustive list of approaches, but rather, some ideas that researchers could utilize, and build from, based on their context of research, as a means to embrace reflexivity within research practices. We specifically highlight the processes used within this participatory filmmaking project with children with disabilities, which included researcher journaling, dialogical shared reflexivity, as well as visual tools to guide reflexivity.

The most common method for researcher reflexivity is through maintaining a researcher diary, where a log of ideas, observations, readings, apprehensions, joys, and surprises within the research process and outcomes are noted (Newbury, 2011; O’Reilly, 2005). In turn, a research diary acts “as a melting pot for all the different ingredients of a research project - prior experience, observation, readings, ideas - and a means for capturing the resulting interplay of elements” (Newbury, 2011, p. 3). Within the scope of this participatory filmmaking project, the first author maintained a researcher diary/journal and made notes as much as she could about the context, process, challenges, tensions, supports as well as her emotions throughout the research process. These notes were often written after she was back from the field as it was impossible to write when working alongside children and doing activities with them in their community. Although she tried to write notes as often as she could after every meeting and situation encountered within the project, there were many instances when it was hard to write thoughts down especially in moments when the process was challenging or emotionally burdensome to reflect on. One such example was that when the project was wrapping up in the field, she can mentally picture how hard the process of saying goodbye to the group was, while also wondering whether or not this project did good for the children involved. In turn, she was not able to write many of her thoughts down as there was immense sadness when leaving the field, letting go of relationships, as well as thinking about unaddressed struggles. As
such, emotions are an undeniable component of any research work (Borg, 2001). Although research diaries have been positioned as ways to support researchers, especially those working alone in the field, in recording as well as processing of emotions (Borg, 2001), it was still hard.

However, engaging in shared reflexivity further supported this reflexive process. This process of shared reflexivity could be with co-facilitators, collaborators, participants or anyone considered as critical friends, who “fully understand the context of the work presented and the outcomes that the person or group is working towards” (Costa & Kallick, 1993, p. 50). Within this participatory filmmaking project, the two facilitators engaged in shared dialogic reflexivity with each other at different points in time during the process. They acted as critical friends, by listening to each other, questioning their understandings, interpretations, assumptions as well as expectations, as means to make progress with the research in an ethical manner (Appleton, 2011).

Another effective way for engaging in reflexivity is through the use of photos, creating visual diaries (Newbury, 2001), or using reflexive drawings (Calvo, 2017). Visuals often complement written notes and support in the recalling of lived experiences (Calvo, 2017). Although the facilitators did not personally use visual diaries, shared reflexivity with children often included the use of visuals. For instance, when wrapping up this project in the field and it was time for goodbyes, some photos that were captured by the group during this process were shared with the children as a video as well as a book. These visuals reminded children about the process they were involved in, the friends they made, in turn, supported dialogic shared reflexivity about their experiences within the process. Furthermore, children when making goodbye notes, drew images of them holding the first author’s hand, which visually portrayed and highlighted their experiences through the participatory filmmaking process as well as their emotions at that point in time.

Engaging in reflexivity is a form of research in and of itself, where the research process, and researcher’s/co-researchers’ self, become the objects of research (Newbury, 2001) and their experiences are transformed into new knowledge (Enosh & Ben-Ari, 2016). Certainly, participatory and transformative forms of research embody sharing and
negotiation of power between the researcher and participants, with participants considered as co-researchers and researchers simultaneously considered as participants. By looking inwards within ourselves and drawing out reflexive accounts of experiences, an often hidden aspect within published manuscripts (Newbury, 2001), there is added richness, honesty, and research authenticity that is obtained (Appleton, 2011). Indeed, engaging in reflexivity can support the collective responsibility for us to engage in socially and ethically responsible research practices.
5.6 References


Chapter 6

6 Issues of Occupational Justice Prioritized and Explicated by Children with Disabilities from Rural India

This paper presents findings of a participatory action research (PAR) project, integrating the Youth PAR (YPAR) approach, with children with disabilities from a rural village in Southern India that employed participatory filmmaking to work towards equitable collaboration of children with disabilities as co-researchers (Benjamin-Thomas et al., under review). YPAR is an approach to research that is focused on engaging with children as co-researchers and collaborators in examining issues of injustices in relation to their everyday experiences and determining relevant actions (Cammarota & Fine, 2008; Rodríguez & Brown, 2009). Specifically, the occupational experiences of children with disabilities, the ways in which occupational injustices were situated within contextual forces, and what they prioritized as areas for social transformation, are presented. ‘Occupation,’ which broadly refers to the ‘doing’ of everyday activities, has been proposed as central to human well-being which is connected to a sense of ‘being,’ a process of ‘becoming’ through shaping individual and collective identity, and influences ‘belonging’ within social and spatial elements (Huot & Laliberte Rudman, 2010; Kinsella & Durocher, 2016; Wilcock, 1998). Embodying an occupational perspective, referred to as “a way of looking at or thinking about human doing” (Njelesani, Tang, Jonsson, & Polatajko, 2014, p. 233), creates a unique space to understand the situatedness of everyday injustices (Townsend, 2015). In particular, taking up a critical occupational perspective (Njelesani, Gibson, Nixon, Cameron, & Polatajko, 2013) also referred to as a critical occupational science perspective (Laliberte Rudman, 2018) acknowledges occupation as “a site where inequality and social difference are constituted” (Angell, 2014, p. 105). As well, this perspective highlights the importance of attending to how injustices are experienced through occupation, and how such injustices are situated within, and shaped through, socio-political, cultural, economic, and other forces (Kinsella & Durocher, 2016; Laliberte Rudman, 2013). Such everyday injustices are referred to as occupational injustices, defined as situations when occupation has been “barred, confined, restricted, segregated, prohibited, underdeveloped, disrupted, alienated,
marginalized, exploited, excluded or otherwise restricted” (Townsend & Wilcock, 2004, p. 77).

A critical occupational science perspective also attends to power relations that shape and perpetuate axes of privilege and disadvantage in relation to occupation (Laliberte Rudman, 2018; Njelesani et al., 2013). This perspective embodies intents to mobilize transformative agendas addressing occupational injustices, seeking to expand possibilities for meaningful occupations (Laliberte Rudman, 2010) and simultaneously restrict occupations that are exploitative of individuals and collectives (Hocking & Whiteford, 2012). By explicating the forms of occupational injustices experienced by social groups from diverse geographical and cultural backgrounds, critical occupational science scholarship aims to create nuanced understandings of occupational injustices as they are embedded within specific contexts (Benjamin-Thomas & Laliberte Rudman, 2018; Farias, Laliberte Rudman, & Magalhães, 2016; Kinsella & Durocher, 2016). Such scholarship seeks to problematize and address contextual forces shaping such injustices, rather than viewing individuals experiencing injustices as deficient and as in need of ‘fixing.’

Children with disabilities are a social group embodying heterogeneous experiences of occupational injustices, with previous research demonstrating diverse ways such children can be denied opportunities for occupation, such as play or schooling, at home and the community (AlHeresh, Bryant, & Holm, 2013; Law, Haight, Milroy, Willms, Stewart, & Rosenbaum, 1999; Tonkin, Ogilvie, Greenwood, Law, & Anaby, 2014). The exclusion of children with disabilities from occupational possibilities is often greater within communities in the Global South where “they are often condemned to a poor start in life and deprived of opportunities to participate in society” (Parnes et al., 2009, p. 1176), and may experience increased violence and mortality rates (Njelesani et al., 2018; Parnes et al., 2009). As such, the occupational injustices faced by children with disabilities within the Global South are shaped through a range of contextual forces, such as a lack of sufficient economic resources to facilitate their participation as well as the stigma associated with disability (Anees, 2014; Singh & Ghai, 2009).
Although the experiences and voices of children with disabilities have been positioned as central to informing change within child rights-based discourses (United Nations Children’s Fund, 2007), their “testimony is often ignored and dismissed” (Parnes et al., 2009, p. 1176). Specifically, children with disabilities within communities in the Global South are often positioned as research subjects rather than active collaborators in research and are “rarely asked about general life experiences such as friendships, consumption, the environment…” (Wickenden & Kembhavi-Tam, 2014, p. 403). The first-hand perspectives of their everyday experiences can deepen understanding of the heterogeneous nature of disability-related injustices, challenge the taken for granted troubling notions of disability that position them as ‘dis-citizens,’ and promote avenues for their participation in society (Devlin & Pothier, 2006). Certainly, their first-hand perspectives have the potential to problematize dominant ‘Northern’ and ‘adult’ models of disability (Meekosha, 2011; Watson, 2012; Wickenden & Kembhavi-Tam, 2014) and guide transformation in ways that are locally relevant.

Within occupation-based scholarship, perspectives of children with disabilities, particularly those from the Global South, also remain at the margins, as the scholarship has been dominated by Western, middle-class, Anglophonic, female, able-bodied perspectives (Hammell, 2011; Hocking, 2012; Kantartzis & Molineux, 2012; Magalhães, Farias, Rivas-Quarneti, Alvarez, & Malfitano, 2019). Additionally, although occupation-based scholarship has raised awareness of diverse occupational injustices and generated knowledge about their situated production, few studies have incorporated an action agenda (Benjamin-Thomas & Laliberte Rudman, 2018). In turn, critically attending to the perspectives of children with disabilities from the Global South through PAR can further explicate nuanced understandings of the situated nature of occupation and occupational injustices and inform transformative agendas (Benjamin-Thomas & Laliberte Rudman, 2018; Farias et al., 2016).

This paper presents findings derived from a PAR project focused on occupational injustices that employed participatory filmmaking with children with disabilities as co-researchers from a rural village in Southern India (Benjamin-Thomas et al., under review). Following an overview of the study approach, the findings are presented within
three key sections. First, highlighting the voices of the child co-researchers, the results from a participatory thematic analysis carried out in collaboration with children with disabilities are presented. Second, a theoretical analysis of information generated by child co-researchers as well as from multiple types of actors, such as parents, service providers, and community members, who influenced the context in which the children negotiated their occupations and faced occupational injustices is presented. This section further explicates how the prioritized individual and community issues raised by the children are situated within contextual forces. Within the last section of the findings, proposed solutions by child co-researchers, addressing the identified occupational injustices, are summarized and considered in relation to the contextual forces perpetuating such injustices. As well, the types of transformation expressed as occurring through the participatory filmmaking process and through the dissemination of the video thus far are presented. Within the discussion, we reflect on the utility and transformative potential of the methodology used, and relate the knowledge generated to existing literature pertaining to children with disabilities in the context of India and to the situated nature of occupation and occupational injustice.

6.1 Project Description

A three-phased PAR project, utilizing participatory filmmaking as a research methodology (Benjamin-Thomas, Laliberte Rudman, Cameron, & Batorowicz, 2018; Mitchell, Milne & de Lange, 2012), was carried out with children with disabilities residing in a rural village in Southern India. As a PAR project, the goal was to embody values of equitable collaboration and social transformation (Benjamin-Thomas, Corrado, McGrath, Laliberte Rudman, & Hand, 2018). Specifically, we aimed to facilitate the collaboration of children with disabilities as co-researchers and social actors, through challenging power differentials between academics and community members.

The objectives were to: a) collaborate with children with disabilities in identifying barriers and supports to occupational participation; b) engage them in a process of envisioning what they needed and wanted in terms of their occupational participation at home, school, and the community; c) work with them and key community stakeholders towards enhancing understanding of how barriers, and resulting occupational injustices,
were produced and, in turn, use knowledge generated to inform transformative directions. An overview of the different phases is presented in Table 8. A detailed description of the different phases of this PAR process and the activities carried out in each phase are provided in chapter four (Benjamin-Thomas et al., under review).

Table 8. Overview of Project Phases

<table>
<thead>
<tr>
<th>Phase 1: Preparatory Phase</th>
<th>Phase 2: Participatory Research Phase</th>
<th>Phase 3: Action Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strengthening local collaboration; Recruitment of children with disabilities; Selection of equipment</td>
<td>Rapport building; Identifying &amp; prioritizing issues; Choosing a methodology; Training of children; Video making through shared reflection and analysis; Dissemination of short film; Wrapping up the participatory video making and dissemination phases</td>
<td>Proposing solutions; Creation of action teams</td>
</tr>
</tbody>
</table>

6.2 Methodology & Methods

6.2.1 Participatory filmmaking

Participatory filmmaking involves community members creating videos to document, explore, and critically engage with social issues (Benjamin-Thomas, Laliberte Rudman, et al., 2018; Gubrium & Harper, 2013; Mitchell, Milne & de Lange, 2012). This methodology is rooted within the work of Paulo Freire (1993) on critical consciousness raising, which is defined as “learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality” (p. 17). Specifically, people situated as experiencing injustices engage in shared dialogue as a means to gain critical consciousness surrounding their experiences of injustices and address social transformation. The process of developing, producing, and disseminating the film provides an occupational means to facilitate such dialogue.

6.2.2 Research context

This project was carried out through a community health department of Christian Medical College and Hospital, Vellore, India, which has been providing health, development, and training services in a geographical area encompassing approximately 85 villages in
Southern India since the 1960s (Muliyil et al., 2018). More specifically, this project was carried out in one village within this geographic area with a population, according to the 2011 census, of just under 5,000 people (Indian Village Directory, 2019).

6.2.3 Researcher positioning

This project was carried out as a part of the first author’s PhD thesis work. Her interests in exploring first-hand perspectives of children with disabilities are rooted within her past experiences as a pediatric occupational therapist in rural India. She was often a witness to situations of exclusion and injustices that children with disabilities experienced in everyday life. She also completed her undergraduate education at Christian Medical College, Vellore, and was familiar with the research context, and had an established relationship with the local institution through which this project was carried out. She spent eight months in India carrying out this project, but collaborations with co-investigators from the local institute were initiated many months prior to initiating the project in the field.

6.2.4 Participants

6.2.4.1 Primary participants

Recruitment was carried out with assistance from local health care providers, using the following inclusion criteria for the children: a) identified by health care practitioners or community members as experiencing disabilities (physical, intellectual or psychosocial); b) having the cognitive skills necessary to understand and participate in the research process; c) aged 10-18 years; d) able to communicate verbally or non-verbally with or without an assistive device; e) interested in using a camera for sharing their experiences; f) residing within the identified village where this project was carried out. The primary participants included six male children with disabilities, aged between 10-17 years, some of them formally diagnosed with an impairment and some not (See Table 9 for participant overview). This group size was within the range of other published studies that had used visual methodologies to engage with children with disabilities in a participatory fashion (Phelan & Kinsella, 2014; Ha & Whittaker, 2016). The group size also enabled opportunities for modifications to the processes to support each child’s participation.
### Table 9. Overview of Primary Participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age (years)</th>
<th>Impairment</th>
<th>School Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shivam</td>
<td>10</td>
<td>Visual impairment (80% blindness)</td>
<td>Attending school (Grade five)</td>
</tr>
<tr>
<td>Sanjith</td>
<td>11</td>
<td>Intellectual disability and hyperactivity (not formally assessed)</td>
<td>Attending school (Grade four)</td>
</tr>
<tr>
<td>Karthi</td>
<td>14</td>
<td>Past history of a psychiatric condition (no present formal assessment)</td>
<td>Out of school</td>
</tr>
<tr>
<td>Velu</td>
<td>11</td>
<td>Speech and hearing impairment</td>
<td>Attending a school for children with speech and hearing impairment (Grade six)</td>
</tr>
<tr>
<td>Arun</td>
<td>11</td>
<td>Intellectual disability</td>
<td>Residential institute for children with disabilities</td>
</tr>
<tr>
<td>Kumaran</td>
<td>17</td>
<td>Intellectual disability</td>
<td>Residential institute for children with disabilities</td>
</tr>
</tbody>
</table>

Note. All children were from low socio-economic backgrounds as all parents, within the demographic questionnaire, highlighted that they did not have enough money for necessary resources.

Although there were six children involved within the scope of this project, only three of them were consistently involved in creating the participatory film due to numerous challenges to participation, which are addressed in detail in chapter five (Benjamin-Thomas, Laliberte Rudman, & Gunaseelan, in preparation). The three children included Shivam, Sanjith, and Karthi. Although Velu attended multiple meetings, he was unable to participate fully due to communication barriers informed by a faulty hearing aid (which his family could not afford to repair) as well as his mother’s safety concerns regarding issues of child trafficking. Additionally, Arun and Kumaran were engaged with as a separate group for a shorter period, during the few weeks they were home in their community on vacation from a residential hostel.

#### 6.2.4.2 Secondary participants

Secondary participants included community members (four teachers, eight parents, six health care providers, and six special educators) who shared their perspectives, through group meetings (or individual interviews when preferred), about the occupational
experiences of children with disabilities. Additional secondary participants were those who participated in discussions during the eight screenings of the participatory film, including, parents, doctors, nurses, social workers, occupational therapists, and occupational and physiotherapy students. Data from secondary participants was collected to deepen understanding of contextual factors shaping the occupational injustices and community issues raised by the children. As well, data from the video dissemination enabled exploration of reactions to the video produced, and dialogue regarding ways forward that involved various stakeholders as members of action teams.

6.2.5 Data generation

Data generation among primary participants aimed to be a participant driven, dialogic group process (Asaba, Laliberte Rudman, Mondaca & Park, 2015; Gubrium & Harper, 2013). Specifically, child co-researchers participated in approximately 35 group meetings and engaged in shared dialogue surrounding occupation-based issues they deemed as relevant to their lives and as priorities for social transformation. This dialogic process, which was supported through the use of visuals (e.g. Post-it notes, culturally relevant drawings, videos captured by children), embodied commitments to negotiating understanding, and challenging of assumptions, interpretations, and thoughts, including the researchers’ (Gubrium & Harper, 2013). As well, this dialogic group process was a central component within the participatory filmmaking process. Details regarding the focus and activities carried out in each meeting are presented in chapter four (Benjamin-Thomas et al, under review).

Data among secondary participants was generated through five one-on-one interviews with parents, three group meetings with different service providers (i.e., teachers, special educators, health care providers) and eight dissemination meetings with parents, health care providers, village leaders, and occupational therapy and physiotherapy students.

All meetings and discussions were audio recorded, and those conducted in Tamil were translated to English by the first author with the support of a local retired school teacher from a neighbouring context. Specifically, meetings/interviews with child co-researchers, parents, village leaders, and some service providers (i.e., teachers, special educators,
village health aide), were carried out in Tamil; and meetings with other health care service providers from the local institution (i.e., occupational therapists, social workers, doctors, nurses) and occupational and physiotherapy students, were predominantly in English, with the exception of when children were present during dissemination meetings.

Overall, information generated through the participatory filmmaking process encompassed different levels: primary texts, product texts, and audience texts (Gubrium & Harper, 2013). Primary texts refer to the media produced by the children (e.g. film and its components), which represent information generated from “what?” questions addressing the video/ narrative making process such as “what issues do research participants define as problems?” (Gubrium & Harper, 2013, p. 186). Specifically, in this project, questions presented within the SHOWeD approach commonly used within Photovoice (Wang, Cash, & Powers, 2000) were utilized to facilitate shared reflection and dialogue among children, which encompassed: what do you see here? What is really happening here? How does this relate to our lives? Why does this problem, concern, or strength exist? What can we do about it? Product texts refer to answers generated to questions relating to the “how?” of the filmmaking process and encompasses information with regard to the process related to creating final products (Gubrium & Harper, 2013) and power negotiations within that process. Product texts included shared reflexive dialogues among the facilitators as well as with child co-researchers about the participatory filmmaking process, and notes from the first author’s journal. Audience texts refers to the responses of individuals and groups to the final visual product (Gubrium & Harper, 2013). In this study, audience texts include discussions following community screenings.

6.2.5.1 Data analysis

Data analysis encompassed two processes, namely, participatory thematic analysis carried out in collaboration with children with disabilities, and a theoretical analysis informed by a critical occupational science perspective (Laliberte Rudman, 2018; Njelesani et al., 2013) and critical disability perspectives (Devlin & Pothier, 2006; Goodley 2013; Hosking, 2008; Meekosha & Shuttleworth, 2009) carried out by the first
author. These two forms of analysis together informed the understanding on the situated nature of occupation and occupational injustices and the analysis focused on addressing transformation. The Quirkos qualitative software (version 2.0, Quirkos Limited 2018) was used for supporting the analysis process.

6.2.5.2 Participatory thematic analysis

This analysis encompassed the process of creating and generating the primary text (i.e., the media produced by children). Specifically, children with disabilities engaged in discussions to identify issues they wanted addressed. Once issues were identified, they further engaged in shared dialogue and reflexivity using visuals (i.e., their captured videos) to explicate the causes and consequences of these issues, and how we could go about addressing these issues. This dialogical process informed the key contents of the film and is referred to as the participatory thematic analysis.

6.2.5.3 Theoretical analysis

Theoretical analysis was carried out to further explicate power relations and the situated nature of occupation, occupational justice, and disability related experiences. Data generated from child co-researchers and secondary participants were analyzed by the first author using a theoretical lens informed by critical occupational science and critical disability perspectives. The critical occupational science perspective informed analytical questions pertaining to the situated nature of occupation and social power relations (Laliberte Rudman, 2018; Njelesani et al., 2013). More specifically, the occupational justice framework (Townsend & Wilcock, 2004; Wilcock & Townsend, 2000) was drawn upon to explicate how issues of occupational justice are situated and negotiated by children with disabilities within the context of this work. The second theoretical lens, that is, critical disability perspectives was used to understand first-hand disability related heterogenous experiences, challenge taken-for granted norms, and deconstruct the existing disability scholarship (Devlin & Pothier, 2006; Goodley, 2013; Hosking, 2008) with voices of children with disabilities from the Global South whose perspectives remain at the margins.
The theoretical analysis process implicitly began when the first author was in the field working alongside child co-researchers in the filmmaking process as well as when she engaged in the process of translating and transcribing data, which informed ideas for analytical consideration (Saldaña, 2016). These opportunities for engaging and re-engaging with data facilitated her immersion within the data and the context where it was generated, which deepened her understandings on the information generated. Once information was translated and transcribed, she engaged in multiple, iterative, whole-text readings of all transcripts and reflexive notes and conducted a simultaneous coding process where smaller codable moments were identified (Saldaña, 2016). All information was theoretically coded based on constructs relevant to critical occupational science and critical disability perspectives which facilitated deeper reflections on the meaning of the data (Miles, Huberman, & Saldaña, 2014). An analysis guide with questions consistent with the theoretical underpinnings supported this theoretical coding process (See Table 10). The codes were re-visited, re-arranged, further grouped, and presented as themes (Charmaz, 2006; Miles et al., 2014); and was further continually refined during the process of writing. Throughout this process of engaging with the data, the first author made notes of her ideas as memos and revisited them through the writing process, which further supported the analysis. Additionally, consultations, involving dialogue addressing emerging codes and themes, with her supervisor supported this process. Overall, the findings presented within this chapter are an integration of the data with the first author’s critically-informed interaction and interpretation that was underpinned by the critical occupational science and critical disability perspectives (Saldaña, 2016).

**Table 10. Theoretical Data Analysis Guide: Examples of Guiding Questions**

<table>
<thead>
<tr>
<th>A Critical Occupational Science Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>How is occupation or occupational participation conceptualized within this transcript? (e.g., How has power and privilege influenced opportunities for occupational participation within this context? What types of contextual influences on occupation are described? Are issues related to the occupations of children with disabilities framed in relation to inequities? To injustices? Or as taken-for-granted?)</td>
</tr>
<tr>
<td>How is the occupational participation of children with disabilities shaped within that specific context? (e.g., What are some barriers to occupational participation that are highlighted at the individual and contextual levels? What are some existing supports to occupational participation? Are there specific spaces where children with ...)</td>
</tr>
</tbody>
</table>
disabilities have reduced opportunities to participate in occupations?)

*What are some themes relevant to the occupational justice framework highlighted within this transcript?* (e.g., When and how are reduced opportunities for children with disabilities to participate in meaningful occupations addressed? Are issues related to restricted or absent occupational participation of children with disabilities seen as an injustice? And how?)

*What are some themes that challenge or expand on existing conceptualizations of occupational justice?* (e.g., What are some positive links to occupational participation at the individual and collective level highlighted within transcripts (e.g., health, well-being, inclusion)? What are some negative links to occupational participation at the individual and collective level highlighted within transcripts (e.g., health, finances)?)

*What are some themes related to the situated nature of occupation and/or occupational justice?* (e.g., What are some cultural, economic and socio-political factors shaping occupational injustices experienced by children with disabilities?)

**Critical Disability Perspectives**

*How is impairment and disability conceptualized?* (e.g., How are impairments and disabilities talked about within transcripts? Where is disability located, in individual, in context, in both?)

*What are some experiences related to disability highlighted within transcripts?* (e.g., What are some disability related experiences specific to the context where this research is carried out? How are these experiences positioned within this context (individual versus contextual level- explain)? What are the numerous contextual forces shaping disability related experiences (e.g., economic, socio-political, cultural)?)

*How are children with disabilities positioned within this context?* (e.g., What are some disability related experiences and expected outcomes specific to children with disabilities? Do children with disabilities have a voice within their community?)

*Participation of children with disabilities within this project* (e.g., How did the participation of children with disabilities within this project impact the children participants at the individual level? How did participation of children with disabilities impact community attitudes and beliefs about disability?)

### 6.3 Ethics

This research project obtained ethical approval from the Western University Health Science Research Ethics Board, London, Canada (Project ID: 110912) and the Institutional Review Board Christian Medical College, Vellore, India (IRB No: 11191) (see Appendices A & B). Overall, some key ethical considerations, consistent with PAR principles (Benjamin-Thomas, Corrado et al., 2018), included, promoting equitable collaboration of children with disabilities, embodying flexibility of the research process,
sharing and negotiation of power, carrying intents for sustainable social transformation, and practicing sincerity within the research process (Tracy, 2010). Recognizing that addressing ethics is an on-going process, ethical tensions were continually addressed through critical reflexivity. Specifically, the first author engaged in a process of individual self-reflexivity as well as shared reflexivity with child co-researchers and her co-facilitator in the field to address ongoing ethical tensions, which has been described in chapter five (Benjamin-Thomas et al., in preparation).

6.4 Findings

The findings of this project are presented in three sections. First, the findings generated through the participatory thematic analysis carried out in collaboration with child co-researchers are addressed, specifically focusing on the individual and community issues related to occupation they highlighted as problematic and how they situated these issues. Themes elaborated within this participatory thematic analysis are key issues presented within the short-film created by child co-researchers. Second, drawing on the theoretical analysis of data from secondary participants and child co-researchers, further knowledge generated regarding how the issues raised by the child co-researchers were situated within, and perpetuated through, various contextual forces is presented. In the final section, emerging themes related to transformation, encompassing proposed directions forward in addressing issues, and experiences of transformation shared by primary and secondary participants, are presented. It should be noted that due to the ongoing nature of transformative work, this final section integrates participants’ data addressing transformation at the time of completion and dissemination of the video.

6.4.1 Participatory thematic analysis

Results from the participatory thematic analysis are presented in relation to four main themes: a) navigating desired occupations within existing boundaries; b) experiences of occupational injustices; c) inter-related social issues of violence and substance abuse; d) environmental concerns related to garbage and deforestation.

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9 https://youtu.be/sPyiQCj82Qs
6.4.1.1 Navigating desired occupations within existing boundaries

Child co-researchers described many occupations they engaged in that were important to them, but also discussed several types of barriers to occupation that were challenging to navigate. Occupations, such as playing local games and music, worshiping in the temple, attending community events, and doing chores at home, were described as sources of enjoyment, ways of connecting with friends and family, and as contributing to a sense of inclusion. For example, Shivam stated, “My grandmother has cows, I usually help by taking it out to the field and giving it water. I really like playing the local drums… I usually don’t play the drums alone but only when there are two or more people to play with me,” while Sanjith shared, “I like fetching water for my house. I like playing games like carrom board, cricket, hide and seek, football, volleyball. I like it a lot… I like worshipping God.”

One barrier to engaging in occupations highlighted by child co-researchers was resistance from parents, which they interpreted as their parents’ attempts to protect them both generally and specifically from violence or child trafficking prevalent within their community. For example, Karthi shared, “I want to go somewhere with my friends but they [parents] won’t let me go. They consult an astrologer and based on that they tell me, ‘don’t go out, someone will do something to you’… They say, ‘you don’t go anywhere, or you’ll end up in a fight.’” Sanjith also stated that his mother refused to allow him to go outdoors at times as child traffickers were said to be in the area. He articulated, “She keeps saying ‘people have come to catch kids, so be quiet and stay back at home.’

Shivam expressed that this issue was a concern even for older children and that parents had to be cautious as the political system was not in a position to protect children: “Apparently the police also don’t do anything, they only catch them and let them out in another location. They don’t put them in jail or anything.”

Child co-researchers in some instances felt like they lacked autonomy and expressed a desire for greater space to make decisions regarding their participation in things they enjoyed doing. As an example, Karthi shared, “What I am trying to say is that, when we do something, people [family members] should not keep telling us ‘you don’t do this’ or ‘don’t do that’… Everyone needs to be able to do what they want, like everyone makes
decisions for us… In some houses they let the children do what they want, but in my house they don’t, they don’t let me do what I want.” In another example, Sanjith expressed his need to participate in occupations in order to be able to gain necessary skills, and described, “He [father] hit me for riding the bike because I might fall, but only by falling will I learn right?”

There were other contextually-located barriers to occupational participation shared by child co-researchers, including a lack of playground spaces as well as economic constraints. Karthi, after pointing out that playing games such as cricket on the streets was not accepted by all community members stated, “We need a ground to play in, because where we play now is full of thorns… Some people don’t like it when we play close to their house and make a noise, or if our ball hits their house and breaks a window, because sometimes we play on the streets.” Shivam, who was very interested in learning to play the drums and the guitar, pointed out the economic constraints faced by his family, “I just don’t know how to play it [musical instrument]…My mother is also thinking of joining me for classes [music], even if it’s there, it costs a lot, 1000 INR per month.”

### 6.4.1.2 Experiences of occupational injustices

In addition to barriers to occupational participation discussed, child co-researchers described situations of occupational injustices by pointing to experiences of marginalization, particularly in school settings but also more generally in their homes and communities.

#### 6.4.1.2.1 Marginalization within schools

Within the context of schools, child co-researchers described restricted opportunities to engage in extracurricular activities, such as participating in cultural programs in school functions and in particular sports activities. The children framed these exclusions as resulting from intentional acts of teachers, connected to perceptions of their impairments and needs. Shivam described, “they don’t include me in school cultural programs, like in dancing. They say, ‘Your glasses will fall off when you dance as you have to jump up and down when dancing, they don’t include me in anything! … They don’t include me as
well as in competitions like running, jumping, and others…” Similarly, Karthi added, “I don’t like the teachers that much. If I volunteer myself for something, they say, ‘we don’t want you’ and call others… They used to say ‘you will not do it well’… They didn’t include me in any school functions as well… they used to choose only leaders, never used to include me. They used to choose students who were good in both.”

Moreover, child co-researchers also situated their marginalization within schools in relation to academic performance, indicating that if their academic performance was not considered adequate by teachers, they were further marginalized within classroom activities. For instance, Sanjith articulated, “They [teachers] will hit me saying, ‘why didn’t you get any marks? And if you’re not getting any marks, why are you coming to school?’ They will also make me sit separately. … They say, ‘even if you get marks, you’re not smart, go sit in a corner!’” Karthi also shared similar concerns during the time he was in school and shared, “They [teachers] compare my marks with others and say, ‘you are a good for nothing, you haven’t done well at all.’”

These experiences of exclusion and marginalization affected the emotional, and in turn, educational experiences of child co-researchers. Karthi pointed out how he had to navigate these emotions and shared, “I used to feel sad… Those participating will go be involved, and those not participating will be with me. But I won’t show it on the outside that I am feeling bad. I used to be with my friends and try and be happy…” These experiences contributed to him dropping out of school. Similarly, Shivam also pointed out, “I won’t feel like going back to this school…I also shout at the teachers, but only in my head.”

Overall, despite these experiences of marginalization in schools child co-researchers also expressed that school was a source of enjoyment and that they desired the opportunity to study. Shivam shared, “I like arranging the benches within our classrooms and sweeping the floor, all of that. I also like writing on the classroom board, studying, and writing in my notebook. I like doing my homework and doing activities.” Similarly, Sanjith also pointed out, “I like going to school because they teach us something, and then they give
us all homework. And if we are just sitting at home it would be boring as no one else would be there. At school we can play with friends.”

6.4.1.2.2 Marginalization within homes and communities

Child co-researchers also described how their experiences of marginalization in schools extended into homes and communities. The children linked their experiences of marginalization at home to their academic performance. For instance, Karthi, shared, “At home, they marginalize you and don’t treat you well if you don’t go to school.” In another example, Sanjith shared, “They will scold me at home, asking, ‘can’t you get better marks and can’t you study?’”

Child co-researchers also discussed their experiences of exclusion from occupations within larger community settings. For example, they described being denied participation in games with other children in their village. They described that other children often assigned them the role of onlookers on the sidelines rather than as players or teammates. Karthi explained, “If I make a small mistake while playing with the other boys, they treat me like my hands don’t work and my mouth does not work, they say, ‘we don’t want you’ and ask me to leave. If I miss a catch once in the game [cricket], they ask me to leave the team, they do that to me! But if they do the same mistake, they won’t say anything, but if I ask them why, they will come to hit me…I will usually be sitting, and everyone used to give their things to me to watch and take care.”

6.4.1.3 Inter-related social issues of violence and substance abuse

In addition to explicating contextual factors that set boundaries on their occupational participation and led to experiences of marginalization in particular settings, the children spoke of larger social issues that not only impacted their own occupations but those of the broader community. In particular, they described various forms of violence, including teasing and bullying and community fights, as well as issues of substance abuse.

6.4.1.3.1 Teasing and bullying

Child co-researchers described their experiences of being teased by peers within and outside of school contexts. They expressed how they were deliberately made fun of by
other children because of their impairment, or because of using an assistive device, and in some instances because of not performing activities according to what was perceived as the norm within their community. Shivam was often teased and called names because of his glasses, as not many children within that rural community wore glasses. He shared, “They keep calling me ‘glasses, grandma glasses, cooking batter to make idlis [round shaped rice cake]’… and they never call me [name], that is by using my name.” In another example Karthi shared the different names he was teased with when he was in school, “They [other children] call me ‘useless’!... They would call me a ‘sissy’ and then they would say so many things like that….,” Sanjith shared about how another child with a speech and hearing impairment was teased, “They call [name] by calling him ‘deaf and dumb’…and also by just mimicking his voice ‘mmm’ ‘mmm’…They verbally abuse him, as he can’t hear, they say so many things…”

As described by children, teasing often escalated into bullying, where children with disabilities were intimidated as well as mistreated by other children both physically as well as verbally. Shivam described his experiences by sharing, “When I am sitting quietly in school, they come and say ‘hey glasses, grandma glasses, come and fight with me if you have courage! They simply annoy me, mainly the children, they will also hit me.” Similarly, Karthi also shared, “Children my age will join the older guys and do this. When I am simply walking, they throw stones purposefully and scold without any reason…They say very mean things, like talk about my mother and all.” Sanjith pointed to the experiences of another child within his school who got bullied, and shared, “They beat him because he has reduced brain growth [intellectual disability]. He doesn’t complain to teachers. He keeps crying if they beat him.”

Teasing and bullying often led to emotional wounds and frustrations within children experiencing this violence, which in turn, was situated as a contributing force to fights amongst children. Shivam spoke about his emotions and actions when bullied and explained, “I feel like I just want to break these glasses!!... I will also get angry and hit them back and then a fight will begin.” Similarly, Sanjith also shared, “I get angry if someone teases me, I will hit them…. Many times during the last day of school, I was in a fight.” In some instances, children wanted to stand up for their peers who were getting
bullied and were emotionally affected when watching others get bullied, as Karthi pointed out, “I was upset and angry with the people who pulled his glasses away. But I was also sad looking at the guy whose glasses were taken away… Because we feel bad, we feel like we also need to tease the people right back. They scold me, and I can shout right back at them, but I end up hitting them.”

The issues of teasing and bullying experienced by children with disabilities were situated as larger contextual issues of discrimination experienced by many children whether they were tall, short, dark, fair, etc. In one example, Karthi discussed the gendered nature of teasing, and commented, “They behave badly with girls, and tease girls.” In another example, Sanjith pointed to how he was teased because he was dark, “They mock me and say, ‘get lost you dark crow!’”

Additionally, issues of teasing and bullying were situated by child co-researchers as an issue experienced throughout the life course and not just among children. They suggested that the language used by adults could be contributing to these instances of teasing practiced by children. Another reason that children gave for this behavior was that it might be considered as ‘fun’. Karthi noted, “The adults themselves speak like that… Some people think it’s fun! They learn it from others, watching others. They even tease animals, like they go with their bikes real close to the dog and make it yell and then they laugh.”

Although child co-researchers predominantly pointed to the negative consequences of teasing, they also acknowledged some benefits. Karthi discussed how teasing, when done in a lighthearted fashion, was considered important for building relationships among friends and family. He stated, “Some kinds of teasing are good, but not all, like teasing that is focused on building relationships is good, like among family members, sometimes it’s fun and that is good for our relationship.”

6.4.1.3.2 Fights within communities

Child co-researchers shared that fights among children, within households, among neighbours, as well as in the community at large, were very common. For instance,
Sanjith shared about his brother getting beaten by his peers, “In his school, they keep hitting my him [brother] and he comes back beaten all the time. They will sometimes ask him for money and take his money from him.” In some instances, fights amongst children were said to become a community issue, as parents were drawn into these fights to protect and stand up for their own children. Sanjith described, “Once someone tells me, ‘you don’t talk to me,’ and puts me aside, we [brother and I] will go away sad, and that is why the parents get into a fight with each other close to home.” He also shared about how family fights within his household were common and he described what he had witnessed right before the meeting one day, “I was riding the bike and [brother] was worshiping God. And my mother that time kept saying that she wanted to go for work, and then my father hit her…."

Child co-researchers pointed to the presence of a gang culture within their community. Specifically, young college going students were said to join specific gangs and engage in fights. Shivam shared, “In this village, if there is a fight among boys that age [college aged], they will make one call, and lorry loads of people will come to fight. Just one call, that is all that is needed.” Additionally, Karthi pointed to how gang fights often involved standing up for their co-members, even if the issues were considered as small. He described, “Like if I come and hit one person and that person has lots of friends, the friends will come and hit the other person, rowdies… They take small issues, make it big, and then have fights where they hit one another.”

Community fights were also positioned as informed by caste differences. Different areas in the village encompassed people from different castes, and it was common for these caste differences to lead to community fights. As stated by Karthi, “There are fights related to caste systems. Like even among small children, they have caste related fights....”

Although fights were considered something that child co-researchers wanted changed, they also positioned ‘hitting’ by parents or by teachers as important for disciplinary reasons. For instance, Karthi claimed, “If they do something wrong then they should get
Sanjith added, “Only then the teachers will discipline them. The teacher needs to hit them, students who are bullies.”

### 6.4.1.3.3 Substance abuse

Issues of violence was also positioned as connected to substance abuse practices prevalent in communities. Specifically, substance abuse by adult men in the community was pointed to by child co-researchers as a predominant factor contributing to fights within households between husbands and wives, and parents and children. For example, Sanjith shared, “When they are fully drunk, they fight with their wives and children at home, they vomit and also ask the mother and children to clean up and then they also break things at home…” Similarly, Shivam articulated a common saying within their community that seemed very real for him as he was a witness to violence within his house. He articulated, “Someone said, if there is a stone in the rice, then they [men] will beat their wives, but if there is a lizard in the alcohol, they will throw it out and drink it.”

Child co-researchers commonly situated substance abuse and violence in economic conditions. As Sanjith expressed, “but my father stopped drinking now because of bad health, but sometimes if he is very tensed then he drinks, sometimes.” On the other hand, children also described how substance abuse caused financial strains within their households, as Shivam shared, “My father also drinks a lot! He doesn’t stop at all, at night he will come and fight with my mother, he has a lot of loans because of drinking, and he will keep asking my mother money, and my mother won’t give him money, so he will hit her. I feel really hurt. It is very hard!”

Child co-researchers not only shared personal consequences from their own family members engaging in this practice, but also shared how children within their community used locally made alcohol, cigarettes, and drugs. They situated this practice as something that was wrong and needed to be changed. For instance, Karthi pointed out, “Guys my age also drink, but I don’t.” High school students from a local school were seen to engage in this practice even within school premises. Shivam described, “In the high school here, the tenth graders on the last day got drunk and created big issues in the school. They drank alcohol and played the drums, smoked, tenth graders!”
In discussions addressing how school-aged children accessed these substances, child co-researchers highlighted that children had access to stores that sold it to them as well as through their older friends. Sanjith shared, “They buy from the wine shop, and they might steal the money from their father.” Karthi in response described, “Not all steal, they might ask their friends to bring it and come for them. They even buy and use substances like chewing tobacco, beetle leaf, local alcohol, cigarette, beer….” In addition, the child co-researchers connected this substance use by other children to improper garbage disposal practices within the community, as children experimented with these substances by picking up empty bottles to take a sip or a fallen cigarette bud for a smoke. For example, Sanjith described, “5-10-year-old children, as soon as they see bottles lying around. They keep it in their mouths and drink from it, even if there is only little… They pick up small buds and put it in their mouths.” Additionally, child co-researchers pointed out that parents were considered as role models, and that children take on this behavior from watching them as well as by being exposed to these substances during local festivals. Sanjith shared, “They watch their father and learn…Another thing is, in festivals many people drink, so small children watch that and start drinking.”

Overall, child co-researchers acknowledged that the issue of substance abuse as a systemic issue contributed by government-run businesses of selling substances, improper garbage disposal, and entrenched patterns across generations. Many individuals were positioned as stuck within this practice, including people in power, requiring more than individual change to address the issue. For example, Sanjith called for closing all the liquor stores by stating, “We should not have Brandy shops, if they exist the men will get spoiled” and Shivam added, “if we remove them, many of our issues will get solved.”

6.4.1.4 Environmental concerns related to garbage and deforestation

Furthermore, child co-researchers addressed environmental issues, specifically garbage accumulation and deforestation, that impacted on, and were impacted by, their own occupations and those of the community.
Garbage accumulation in public spaces within their village, such as the local streets, rivers, temple spaces, and public wells, was identified as an important concern. For example, Sanjith claimed, “People eat in the shop and then just throw garbage right there and leave… chocolate wrappers, fruit skins, chicken legs and packets… If we go via this [name] road, there is garbage collected like a mountain.” Similarly, Shivam also shared, “The common wells, nobody cleans it, they just throw garbage…. Near the temple, there are a lot of bottles and water packets….”

This issue of improper garbage disposal was seen by child co-researchers as affecting livestock, plants, and, in turn, the overall health and well-being of community members. Shivam shared, “The cows also eat the garbage and become ill” and that “The garbage in the wells make the wells dirty, and worms, and mosquitoes, and other diseases can come from it.” Karthi also shared a health-related concern with the burning of garbage, “There is nothing wrong with burning waste, but when burning plastic, the chemicals from the plastic hover around the town, which is very bad for small children.” Additionally, child co-researchers described how leisure occupations of community members was affected through this practice. Karthi pointed out, “They also throw glass bottles in the well, and people who swim in the wells can get hurt.”

Although improper garbage disposal was identified as a contributing factor for initiating substance abuse practices among children, substance use practices were also situated as contributing to garbage accumulation in public spaces. It was posited by child co-researchers that community members engaging in this behavior did it in spaces that did not belong to anyone, and left the space with alcohol bottles, water packets used to mix alcohol, cigarette buds, and other drug packets. Sanjith shared, “People drink and throw it [bottles and packets] right here at night so nobody sees them drinking…some even drink here during the day.” Similarly, Karthi pointed out, “They not only throw these bottles, but they break it and then throw it, look there is one right here. If they throw it in the right place, the garbage collectors can collect it, but if they break it and throw it, many people get hurt in their feet when walking.”
The issue of garbage accumulation was also situated as socio-political and systemic. Certain practices pushed for disposal of garbage and other material in public spaces, and systemic constraints did not allow community members to properly dispose garbage. For example, Shivam pointed to how funeral rituals contributed to water pollution and shared, “People do rituals in the wells when people die, and they shouldn’t do it.” Other systemic constrains included irregularity of garbage collecting vehicles in specific areas in the village, as Sanjith shared, “The garbage vehicle doesn’t come into the inner village streets. It only goes on the main roads… If the garbage vehicle doesn’t come regularly, they throw it in the well, or they burn the garbage, and then it will stink!” Child co-researchers also pointed to systemic barriers as reasons for leaving this issue unaddressed, as Karthi stated, “Only when the councilor is coming, they will start cleaning the place until they come and see it, after that it goes back to normal.”

An increase in deforestation activities within their village was identified as an issue by child co-researchers. They pointed to its consequences for flora, fauna, as well as for people living within their community. The reasons for deforestation were situated within existing needs for space and wood for building houses, for cooking, and for safety reasons related to electricity. For instance, Karthi shared, “They are cutting a lot of trees in our village… Some people say they need it for work and cut down trees. They cut trees and use it for their stoves.” Similarly, Shivam also described, “Because water seeps in through the roofs, they cut trees for new ceilings, and for buildings.” Additionally, celebrating festivals and functions, in some instances, contributed to the cutting of trees, and Sanjith shared, “There was also a big issue in the village for cutting down a Tamarind tree for a festival.” With respect to safety, outdoor electric wires often got entangled with the tall trees, and children highlighted the cutting of trees for this safety reason as a necessity. Shivam explained, “In my house they were worried about the wire that the tree was touching, so they cut it off.” As well, community members were also said to be cautious of insects and mosquitoes residing in dense forest areas as Karthi explained, “People have cut their plants due to mosquito issues as they don’t want disease to spread, so maybe people should plant medicinal plants that prevent mosquitoes from breeding.”
While child co-researchers acknowledged varied reasons contributing to deforestation, some of which they framed as necessary, they expressed concern regarding the consequences of deforestation, connecting it to, for example, water shortages, safety issues, and less useable outdoor spaces. Karthi shared, “By cutting down trees there is no good, only bad. Because of cutting down trees, we don’t get rain that much, and we don’t get enough water. Even in my house we get water only once every two days…. “ Child co-researchers also articulated how the habitats of snakes were affected and brought with it safety concerns for their households. Sanjith shared, “The snakes will come into our village if we cut down the trees… and enter our houses.” Lastly, a need for shade and breeze brought by the trees was situated as essential for outdoor activities. Sanjith described, “If we grow trees, they become big and produce fruit, it also gives us shade…. It gives us breeze…” and Karthi added, “The shade provides us a place to sleep, eat, as well as to cook food.”

6.4.2 Theoretical analysis: Deepening understanding of the situated nature of occupational injustices and issues raised by the children

Within this section, the occupational injustices and issues raised by the child co-researchers through the participatory filmmaking and analysis process are further situated through analysis informed by a critical occupational science (Laliberte Rudman, 2018; Njelesani et al., 2013) and critical disability perspectives (Devlin & Pothier, 2006; Goodley 2013; Hosking, 2008; Meekosha & Shuttleworth, 2009). This is accomplished by integrating analysis of the concerns raised by child co-researchers with information gathered from secondary participants. First, ways in which taken-for-granted understandings of disability served to shape situations of occupational injustices (Townsend & Wilcock, 2004) are addressed. Then, complex intersections of economic, systemic and socio-cultural forces shaping situations of occupational injustices (Farias et al., 2016; Kinsella & Durocher, 2016) are explicated. Finally, the issues of contested responsibility and individualization of occupational injustices (Benjamin-Thomas & Laliberte Rudman, 2018; Farias et al., 2016) are described as contributing to inaction, despite community members recognition of the importance of occupational engagement,
particularly in the context of schooling and vocational training, for children with
disabilities.

6.4.2.1 Occupational injustices faced by children with disabilities

Aligned with the child co-researchers’ descriptions of the occupational injustices they
faced in everyday contexts, integrated perspectives from secondary participants, further
explicated how children with disabilities were often marginalized from participation in
occupations within their homes, schools, and within the community at large. At home,
children with disabilities were described as been viewed as rarely needing avenues for
occupation. Referring to parents, a social worker shared, “Very rarely, the parents realize
that the child has to be taken out and needs to be exposed to the sunlight and needs to
engage with the other siblings and things like that, it is very rare.” Additionally, for
children with disabilities, watching television, and being involved in a passive occupation
was common as the same social worker claimed, “The occupation [for children with
disabilities] is watching tv. The parents engage them just by switching on the tv and
giving a remote to them. Very rarely they play with toys, they don’t even offer them a toy
to play with their siblings. Most of the time they watch tv, that is what is commonly
happening in [name of geographical context].” Additionally, children with disabilities
were denied opportunities to participate in community events on a regular basis by
parents for varied safety reasons, which was also a concern raised by child co-
researchers. For instance, a parent shared how the grandparent of the household was
additionally protective and stated, “Even now, he [grandfather] doesn’t want him to go
out freely and play.”

Within regular school systems, children with disabilities were often denied admission.
The village health aide pointed out that parents often complained to her about systemic
barriers to school, “My husband works, I work, who will take him to school? And if it is
an ordinary school, they aren’t giving him admission…So, this is just like that.” Even if
children with disabilities were admitted into schools, parents expressed concerns, similar
to those of the children, that teachers often denied opportunities for participation in
school-related academic and extra-curricular activities. Parents expressed that the
children were physically ‘included’ but not fully included in school activities. They were
made to sit alone in a corner of the class during lectures as well as intentionally not chosen for extra-curricular activities. A parent shared,

“He likes to dance just like other boys and is interested in being a part of activities, but the teachers keep saying that ‘you have a problem with your eyes, and something might happen to you’ and are not including him in school activities and programs. He will then come home and cry. Even if I go and tell the teachers to include him, they will say that ‘if something happens to him, then we will be blamed’ so they don’t want to take the risk. So, he keeps saying that ‘they don’t include me in any activities’ and cries! What can we do?”

These situations of occupational injustices extended into institutions where children with disabilities were sent to reside. Specifically, children with disabilities were not provided adequate opportunities for play and other occupations and were also restricted within physically enclosed spaces. For example, Kumaran shared, “They lock us inside the hostel and don’t let us out. We only have to be inside. They have the keys. If we come out, they will hit us… We only play ball, nothing else. We have to sit quiet, if not, they will hit us.” Additionally, they were disciplined for behaviours considered as inappropriate within that context, without consideration of ways that behaviours might be linked to their impairments. For instance, Kumaran pointed, “If we do wrong, they will hit us with a stick. They have hit [name of another boy] because he was simply laughing too much. The helper, and teacher, saw him laughing and they hit him.” These disciplinary actions and physical constrains further contributed to situations of occupational injustices.

6.4.2.2 Situating occupational injustices within taken-for-granted notions of ‘disability’

Within this South Indian rural context, children with disabilities were often positioned by family and community members as ‘not normal’ and, in many instances, their existence was considered to be an outcome of sin. A social worker put it this way, “The family who has got a special child, in the community, or in the house, they think it is a curse or an outcome of sin, so they don’t end up looking at the child as normal or can be compared to
An occupational therapist pointed out, “And even the other members in the community, they just think about some superstitious beliefs and stuff, which is very common, because of maybe ‘his father is not good’ or ‘his grandfather is not good.’ These kind of things come up when we talk, like ‘I don’t know what kind of thing his mom did.’” In turn, it was common for children with disabilities to experience social isolation and occupational marginalization (Durocher, Gibson, & Rappolt, 2014; Stadnyk, Townsend, & Wilcock, 2010; Townsend & Wilcock, 2004) within their homes and communities. Another occupational therapist shared, “The first thing is, being isolated. That is, children with disabilities are kind of isolated from the family as well as the same age group people, and mostly they are treated like untouchables.” Within homes, parents were described as sometimes providing less care to a child with disabilities when compared to a sibling without disabilities. A community health doctor described,

“These mothers feel that only if there is a very morbid stage, like they end up in a seizure, or end up having pneumonia, which is not settling in one or two weeks, they come [to the hospital], they don’t come otherwise. Only for a normal child, parents come even if the kids have a one-day fever. If the child has a disability, they wait, and they are willing to wait even for like almost ten days. Then they come with the most morbid state and then it becomes difficult for the health care provider to even treat the patient. The sense of neglect is there in the family and that we cannot avoid…if that can be change it will be good.”

Neglect was also described in instances where children with disabilities were denied basic resources like food and hygiene. A social worker shared, “Some families I have seen, they don’t want to even give three meals because to be frank the mother says, ‘anyways he will be passing stools if he has been over fed, so let him at least starve for one or two times…”” Another social worker added, “They don’t even wash their clothes, they use the same clothes for two weeks, ten days, that’s a problem.” This neglect of children with disabilities within this context was sometimes seen as being pushed to the extreme of “better dead than disabled” (Gupta & Singal, 2004, p. 23). A social worker claimed, “If we ask very deeply, they will be alike ‘it’s okay sir, if they die, let them die,
that’s all.’ That’s what they say.” This nature of isolation or marginalization was articulated by another social worker as, “It’s like almost abandoning the child from the family.”

Situations of neglect were shaped and contributed by notions of ‘incapability’ of children with disabilities (Meekosha & Dowse, 2007; Singal, 2010), as reflected in issues raised by child co-researchers when speaking about their experiences in the school environment. The village health aide expressed, “For these kinds of children nobody thinks that they are able to study.” Similar concerns were articulated by a government appointed special educator, who shared, “When we are able to get their [children with disabilities] talents out, the teachers are surprised.” Together, these socio-culturally shaped issues create situations of neglect and position children with disabilities as ‘incapable,’ leading to limits on occupational possibilities (Laliberte Rudman, 2010) and creating situations of occupational injustices.

Consequently, the negative attitudes towards children with disabilities (Anees, 2014; Singh & Ghai, 2009) and their perceived positions within society as dis-citizens (Devlin & Pothier, 2006) and of lower status and lacking abilities (Wolbring & Ghai, 2015) contributed to parents not disclosing, denying or delaying the acceptance of their child’s disability. A parent, shared, “Some people are not aware of his difficulty, and to some people who ask we will explain, that because of a specific problem he has been asked to wear glasses. Apart from our family members not many people know about it. Even if people come and tell us that he is struggling to find things when walking, we still don’t tell them anything.” An occupational therapist adds, “They also have a ‘stigma,’ they don’t want to bring the child out. See, even they sometimes don’t even take the child to a special school as they feel they will be stigmatized. We have a school in [name of place], but still, I don’t know how many mothers and fathers are bringing the children to the school. Because of stigma, they don’t want to. They say ‘sir, let them be at home only, we’ll manage’ but they don’t know how to manage, that is the problem.” Again, issues of stigma was pointed to as a barrier posing limits to the occupational possibilities (Laliberte Rudman, 2010) for children with disabilities.
Issues and difficulties faced by families led to devaluing and labelling the children with disabilities as the ‘problem’ (Watson, 2012; Vehmas & Watson, 2014) which also led to solutions that aimed at ‘fixing the child.’ Within this rural context, parents visited traditional healers in search of “medical magical remedies” as stated by a social worker, as a means to ‘cure’ their child. A special educator claimed, “Children who are hyperactive, generally get traditional medicine, which include giving them a burn, poking one ear hole to wear a earring, and the traditional doctor goes to their house and gives them counselling and gets them to do this.” This pursuit for a cure is ongoing as an occupational therapist explained, “They [parents] try different methods, like go to different traditional healers, they don’t stick on to one, they keep going.” Even if parents did not approach traditional healers, they often sought biomedical forms of treatment with hopes for complete recovery of their child. A social worker stated, “By going to [name of hospital] they will be fine they think. They think that only medicines will cure them. They think that if they eat medicines they need to speak and walk.”

Attitudes of stigma combined with a lack of available resources and the impossibility of ‘curing’ often led to the institutionalization of children with disabilities. For some parents, admission of their children into a residential facility for children with disabilities became the best available option for them and for the child, considering issues of safety and available resources. The father of Kumaran and Arun who were living in a residential hostel for children with disabilities shared, “They [doctors] said, ‘you are keeping them at home right, why can’t you put them in the hostel?’ and then we asked, ‘is it better to keep them at home or join them to a hostel?’ and the doctors said that ‘admit them to a hostel and they will take care of them well.’” This father also expressed,

“For them living in the hostel is only good because this one time [name of child] burnt our hut down, and during that time, his mother was in the house. I had gone to [name of city]. The police and the fire department crew had all come. However, there was no access for the vehicle to come to our house, they could come only till a certain point. It is very difficult for us to even manage them [children with disabilities] even for ten days when they come home. When they are home, we
cannot go anywhere…. I think they are doing well. They are safe there and I am satisfied.”

Indeed, parents were not in a position to view the occupational needs of children with disabilities as a priority within situations of chronic poverty, thus further shaping restrictions in occupational possibilities for their children.

6.4.2.3 Complex layers of economic, systemic, and socio-cultural forces shaping occupational injustices

These issues of occupational injustices experienced by children with disabilities were further described as shaped and perpetuated by diverse contextual forces (Farias et al., 2016; Kinsella & Durocher, 2016). Namely, economic, socio-political, and cultural forces, informed and perpetuated situations that limited occupational possibilities for children with disabilities, and in turn contributed to occupational injustices.

Economic constraints experienced by families of children with disabilities from a lower socio-economic status informed what occupations children were and were not able to participate in. Specifically, when parents needed to prioritize finding ways to meet basic needs such as providing food for the rest of the family, occupational needs and wants of the child with a disability were often positioned by parents as a luxury. For instance, a parent contextualized the occupational interests of her child with a disability and the limits to occupational possibilities when she said, “He is very interested in music, and he has been asking since he was young, but we are the ones not in a position to join him for classes. If the cost was cheaper, we would have somehow struggled and joined him, but it is hard to look after the first child as well as the second. So, we have told him that we will try, and he needs to wait.” Additionally, occupation was situated as secondary to primary needs like food and shelter, and the father of the Arun and Kumaran shared that the hostel for children with disabilities where his two sons lived was able to provide for these needs, which in turn, gave him a sense of satisfaction and reduced the amount of stress that he carried.

Moreover, the limits parents set on the occupational participation of children with disabilities outside of their homes were also shaped by economic constraints. Parents
wanted to protect their child from getting hurt especially since violence among children, through teasing, bullying, and fights, was common, and brought with it financial consequences. Parents incurred additional costs when their child was hurt, for which they may not have sufficient finances. A nurse shared, “Yes, they [parents] are kind of protective. They don’t want anything to happen to the child as it is kind of an extra burden. Like if something happened, like if they go out of their house and something they hit or fall or something happens, then it’s like an extra charge for them with additional medical issues and all, so basically, they want the child to stay safe. That’s all.” This concern was further described by a parent, “He very often breaks his glass frame, at least once in six months, and the frame and lenses costs 2500INR. It is because of playing with the kids only all these issues come, and if we tell him to stop, he won’t listen. He is happy doing things his age. But it is hard for us.”

The type of schooling children with disabilities received was also informed by parents’ economic capacities. Within an Indian context, an English-speaking private school is often socially looked at as the best possible schooling for all children, irrespective of ability status, to support their development and learning. However, children with disabilities from rural and lower economic backgrounds were often denied that opportunity due to their additional medical expenses. In one example, Shivam had to be moved from an English speaking school to a public Tamil speaking school, and his mother pointed out, “Due to his surgery, we had to spend a lot of money, and we could only afford a Tamil school, so he is in a Tamil school now.” Public schools in rural Indian contexts often lacked additional resources, in terms of human and material resources, to facilitate inclusion of children with disabilities in their day to day school-related activities. In turn, children with disabilities experienced marginalization within rural public-school settings and lacked a holistic educational experience.

The lack of human and material resources within rural public schools was systemically shaped and existed across all public rural school systems within this context. Although government policies and structures mandated the inclusion of children with disabilities in schools, their realities embodied experiences of exclusion. Schools lacked the necessary resources to support the full participation of children with disabilities in many school-
related activities. Specifically, teachers lacked training on how to work with children with disabilities to facilitate their full involvement in classroom and other school-related activities. A public-school teacher shared, “They give general training to us but not special training to deal with these children. If they give us special training, it will be good for us. We cannot do anything to help the children wholeheartedly with this general training.” Physical inclusion in schools, rather than inclusion within school activities, was considered more than enough, and another teacher claimed, “We received only half to one day training. Helping those children mix [within the same physical space] with other children is a great thing, and that is all we can do.” The lack of training for teachers and others working in the school system was pointed to as a lapse in the system by a social worker. She shared, “It is all written in papers, and the government yearly produces a lot of projects and schemes, but if you really ask the local district academic officers, they doesn’t know anything; if you ask the school teachers and head mistress/master, they don’t know about integrating a special child within the school… It is only there in paper that they can integrate special children…..”

Moreover, the limited number of teachers within each school added another layer which contributed to situations of occupational injustices for children with disabilities. A teacher shared, “Even if we receive training, it is still difficult…there needs to be a one to one ratio between teachers and these children.” This issue was also described by a parent who shared, “With 100 children in the class, the teachers don’t know who is present or absent. They will take care of him like how they take care of the other 100 children.” The lack of human and other types of resources addressing teacher training within public school systems pushed children with disabilities to special schools and institutions for children with disabilities. A special educator shared, “The teachers keep telling us to put him in a special school. So if we ask them ‘then why do you have this education/training?’ they say that ‘we have so many children and we cannot do any individual care for them, so you are there for that purpose only. You can see and take care of them.’”

Although systems were established for addressing better inclusion of children with disabilities in school through government appointed special educators, there were gaps in
services. Special educators articulated that they themselves lacked sufficient training to be able to transfer the skills to the teachers. A special educator described,

“First, there are trainings at the state level and then people who get the training come to the district level and train staff at the district level… if he has heard 75% of the information, only 25% will get shared to staff in the next level, and by the time it reaches us at the block level only 5% of the information is transferred. We at the block level are not able to use this information to conduct a five-day training with the teachers… If the staff at the state level has a good lunch and falls asleep at the training, the story ends right there.”

In addition, there were only a hand full of special educators who had to provide services across multiple villages in the area, and in turn, they visited each school approximately once a month. In turn, there was a lack in continuity of training with children as the teachers were not able to follow through. A teacher shared, “Once a month, they [special educators] come for half an hour to spend with the child. But 30 minutes isn’t sufficient. They need to come daily; it would be nice. If there is no chance of bringing them daily, it is better for us to send the children to the special school.”

Another systemic barrier that contributed to situations of occupational injustices for children with disabilities was related to issues of transportation. Children with disabilities were provided with free bus passes as means for accessing basic services like health care as well as for occupational needs like schooling. However, they had no means to use these bus services due to physical as well as social barriers. A social worker shared, “Even our transport system, they don’t allow differently abled children to get into the bus. They [bus driver and conductor] don’t wait!” and another social worker added, “But interestingly, they have given a free bus pass, useless bus pass, because they [children with disabilities] can’t even get into a bus.”

Even for children with disabilities who were out of school and wanted to have an education, systemic factors seemed to work against school return. Older children felt out of place in schools where their peer groups were in a higher grade than them, as it is not common for schools to have a mixed age group of children within the same grade. A
parent whose son stopped going to school a few years ago shared, “When big children go to study with small children in the same class, it will affect them. They feel awkward!” She also pointed, “He feels bad that he doesn’t go to school… Now he wants to study and is interested, but he didn’t feel this way before. He now feels bad for stopping his studies. Even yesterday we told him that there is no particular age to study, even with grandma he can go study. But he said ‘who will join me at this age? Only schools for the aged might admit me,’ he says and feels bad about it.”

In addition, participants emphasized that policies and systems pertaining to children with disabilities addressed needs only for certain sections of society, primarily people from urban and privileged backgrounds. For example, obtaining government benefits and resources demanded a high degree of formal documentation of disability. As well, in some instances, financial contributions were required as corruption was embedded at different levels within the functioning of these systems. A social worker shared,

“So in that case, the government’s support through the physically challenged pension, even to get that pension she [mother of a child with disabilities] has to spend a lot, and she has to hear a lot of stories from the community, and also there is bribing and a lot of corruption and things like that. They need a lot of certificates, and age proof and medical certificates, which are not that easy for anybody to get, other than through [hospitals] and other things, they really struggle a lot.”

As such, in agreement with the assertion that disability is one among the multiple axes of oppression (Devlin & Pothier, 2006), occupational injustices faced by children with disabilities from rural backgrounds in this study appeared to result from intersections of having a disability, residing in a rural community, and being from a low socio-economic background. As a social worker shared, “And when we compare the rural and urban, the accessibility, resources, and things, availability of aids and appliances, any training, and any institutions or anything, that is really very, very, very, much restricted in the rural areas. Even the NGOs they have a good set up in the urban area, but they don’t want to extend it to the rural area.” She also articulated that most services for children with
disabilities addresses the “Creamy layer of the society but it is really not getting into the deep...”

6.4.2.4 Contested responsibility and individualization: Shaping challenges in addressing occupational injustices

Like children, secondary participants also highlighted occupations as important for children with disabilities, especially related to schooling and vocational training. However, the contested attributions of responsibility and individualization of issues (Benjamin-Thomas & Laliberte Rudman, 2018; Farias et al., 2016) worked against collective action at the social level.

Specifically, it was put forward that situations of occupational injustices could create repercussions affecting the future well-being of children with disabilities. For instance, experiences of occupational injustices within schools could damage futures as they often led to children dropping out. A parent pointed to this concern and shared, “By the time we wait for the teachers to get trained, our children might get dropped out of school, and they also will end up in doing manual labour work like us.” Some additional consequences were discussed related to mental illness in adulthood. The local community health aide shared, based on her many years of experience working in this community, that “Some of them when they [children with disabilities] get older get mental illness. By thinking that they don’t have any respect within their community, they become ‘psycho.’ If they have no respect at home or in the community, what will happen to them?... Now they [children with disabilities who have grown up] are all 20-25 years old and are all psychiatric patients taking medicines.”

Additionally, schooling opportunities for children with disabilities were situated by parents as central to breaking the entrenched cycle of poverty. Parents described that they themselves did not have opportunities for education, and they positioned their child’s education as extremely important. A parent shared, “We thought that since we are not educated, we have put them in school, so at least they get an education.” Similarly, another parent exclaimed, “If he studies well, he will be able to get a good job. If not, he might have to become a construction worker like his father, who knows, half the people
in the village keep saying that my younger son will become a construction worker only. It is very tough; I don’t want a job like that for him. His father has struggled a lot…If they study well, they will live well.” Indeed, education was seen as a means for instilling hope for a better life for their children.

Given uncertainty about their children’s success within school, vocational training opportunities, where children with disabilities had opportunities to learn skillsets that prepared them for employment, were also considered as important by parents. A parent shared, “We need to do something for their life, like teach them vocational skills, skills that can move them forward in life.” Overall, parents wanted their children to do ‘well’ in life, by being in a position to be able to earn for themselves and their families when they become adults. As another parent described, “If he is given some work and also paid for it, at least he will know that he will get money for work. So, if he learns some vocational skill it will be useful.” This need for vocational training opportunities for children with disabilities was also pointed to by service providers who criticized the government for failing to establish such centers. A social worker exclaimed,

“Very important thing is, the government has also failed in establishing any vocational training institutions for those children. Immediately they have given pension to a 10-year-old, but they didn’t realize that 10 years is the right age, and in the age of 18 you will be a productive child. And if they think about some integrated vocational training centers, then for lifelong the government doesn’t need to spend the 1000 INR. So that is lacking somewhere … And one thing that very well surprised me is, the government could establish liquor stores in all the districts of Tamil Nadu and all the streets, but they didn’t make a good attempt to establish one vocational training institute also.”

Although school and vocation related occupations were situated as important, the individualization of issues and responsibilities with reciprocal blaming of parents, teachers, service providers, as well as children with disabilities impacted social action. First, parents of children with disabilities were problematized as the reason for the injustices experienced by children with disabilities. It was highlighted that parents, while
being surrounded by issues of stigma, often failed to provide occupational experiences for children with disabilities. An occupational therapist shared, “They [parents] don’t train them [children with disabilities] and they don’t take them to school, and even play activities, because of that they are isolated from the normal group.” Parents were also seen as not acknowledging the needs of children with disabilities. A special educator shared, “Even now, there are many parents who don’t co-operate with us. Even if we go and try and speak to them, they will say that, ‘no my child will be this way now but later will be good when they grow up.’ How much ever advice we give them, they don’t listen to us. But after a while, when their problem increases, they come to us. Even people who are educated will do this...” Thereby, parents were often blamed by service providers as being a central factor in limiting occupational possibilities for children with disabilities even when other contextual factors contributed to such situations.

Children with disabilities were also seen as the ‘problem’ by teachers, community members, and parents, with their experiences of occupational injustices located in their impairments or behaviours. For instance, a teacher explicitly positioned children with disabilities as incapable of good academic performance, and shared, “They aren’t able to keep up with the school work.” Teachers were also described as highlighting the limits of children with disabilities in academics; as one parent described, “When he was in school, they [teachers] used to scold him saying ‘buffalo, buffalo, you’re not studying anything, you are just simply sitting here.’” Additionally, community members and parents also situated the ‘problem’ to be within the child. A parent explained, “They [community members] say that ‘he doesn’t study, and he also spoils the other children who study’ and they say that ‘your child doesn’t study well. To help them study we [parents] are struggling, working hard and buying food and everything for them but he is not able to study.’” She also shared, “He has gone to grade five but he doesn’t know anything. What the teacher says is, that because he is too mischievous, he is not able to study properly.” Thereby, teachers, parents, and community members tended to blame the child for failing to succeed without always acknowledging the various contextual barriers limiting opportunities for success.
Parents, service providers, as well as children, often blamed teachers for the experiences of occupational injustices faced by children with disabilities within schools. Specifically, teachers were seen as having a lack of knowledge and skills related to working with children with disabilities. Karthi shared, “They [teachers] are the ones who need to make the children study properly. Some teachers don’t teach properly at all. But they say the students don’t study well and hit them. We should tell them to take class properly.” Teachers were also problematized for not taking ownership or responsibility of working with children with disabilities in schools. A special educator claimed, “There are no teachers who will admit these mild, moderate, severe children and say I will take care.” Additionally, teachers were also blamed for ‘othering’ children with disabilities and looking at them as the issue. A special educator described, “The teachers only don’t know how to do many things, and without thinking, they just keep finding fault of the child.” Teachers were also pointed at for blaming children with disabilities for the mistakes of other children. A special educator shared, “Even if other kids do anything, they will put the blame on these children. They say, ‘because of him, the whole class is disturbed,’ like if he is not there all the other kids will become IAS officers [civil servants]… they make it look like he is the one spoiling everyone’s studies.” The teaching approaches used by teachers was also situated as needing change, as articulated by a special educator, “The children who don’t pay attention to them, pay attention to us… What the teachers say is that, only when you come, they obey and study. They say that these kids don’t obey them. Why don’t they obey them? It is because of their approach or their teaching method, which they don’t know the correct way of doing.” Additionally, parents also blamed teachers for not accommodating their child’s needs, as one parent exclaimed, “We have already told the teachers in the school about how these children feel. But when we tell them they get very angry and get tensed. They act like they are already doing what is right and that by telling we are finding fault…Sometimes, when we tell them, they say ‘yes yes, we will see’ but again, the same thing repeats.” Additionally, teachers’ behaviours and the way they treat children with disabilities was positioned as leading to school drop out of children with disabilities. Another parent described, “He then went [to school] for ten days, and after that only all these issues happened, that is, the teacher hit him and shouted at him because he wasn’t able to learn
English… and then he said he didn’t want to go.” In spite of structural barriers that prevented teachers from fully including children with disabilities in school activities, blame was placed upon teachers for shaping occupational injustices through their individual acts of neglect, incapacities, and attitudes.

Overall, the individualization of issues, through placing the blame on particular types of individuals such as teachers, parents, or children, served to obscure larger systemic barriers that shaped situations of occupational injustices, and worked against collective action.

6.4.3 Transformation as a continuum

Transformation within PAR encompasses a continuum of processes. In this this section, types of transformation addressed at the time of completion and dissemination of the video are highlighted, including: sensitization of community members and service providers about the capabilities of children with disabilities as well as community problematics identified by child co-researchers; a heightened expression of motivation by parents, health care providers, and village leaders to address the issues brought forth by children with disabilities; the articulation of socially transformative agendas through proposed community initiatives and programs; and the personal transformation of child co-researchers through the course of this project.

6.4.3.1 Sensitization: Children with disabilities challenging taken-for-granted discourses and assumptions

While ‘disability’ within this context was linked to perceptions of ‘incapability’ and ‘lower status,’ the children with disabilities involved as co-researchers in this project were able to resist and challenge some of the negative taken-for-granted assumptions regarding their positioning in society (Hosking, 2008; Watson, 2012). Additionally, child co-researchers rarely identified themselves as having a ‘disability’ and always positioned the struggles they were facing within larger contextual challenges faced by all children irrespective of ability status. For instance, issues related to their teasing and bullying were situated as faced by many children with varied types of difference, for example, whether they were dark, fair, tall, short or if their name sounded different.
More specifically, child co-researchers participated in occupations that were considered ‘unsafe for them’ and challenged norms that pushed them to act in certain ways. For instance, they participated in occupations that they liked irrespective of how others in the community positioned their abilities based on their impairments. They played games alongside other children even if they were repeatedly sent to the side lines and persisted in enacting their occupational interests. In one example, a parent shared that teachers often complained saying, “He plays along with other children and doesn’t act like he has any eye problems.” Indeed, the child co-researchers did not succumb to what was expected of them because of their attributed disability status, but rather challenged these assumptions through participating in occupations on a daily basis.

In concert with assertions regarding the power of first-hand perspectives of children with disabilities in challenging negative disability discourses (Watson, 2012), child co-researchers within this project reclaimed their identities (Priestley, 1998) and positioned themselves as talented and capable irrespective of what their family members, peers, or the larger community thought about their abilities, which was also seen through the film they created. The local community health aide shared how parents of children with disabilities recognized the abilities of their children through the scope of this project, “After they [children with disabilities] joined and were interested and took part, did the parents actually think that ‘oh even my child has so many talents.’ After the dissemination meeting, they [parents] said, ‘even our children know this much’ and we are happy. Now they [parents] have an interest and have started asking us [community health team] to please continue working with their children. So, I was happy to hear that.” A parent also shared, “These children have many talents, and we have now seen that. What we don’t know, the children have shown us through the video. The video that the children have made needs to be shared not only with us but also with the general public. Nice that they had the opportunity to do this video, now we know what is on their mind, thank you.” Another health care provider, a community health nurse, shared how this video changed her perceptions on disability, “Actually, before this video, the perception that we [nurses] had about disability was like okay, they can’t do, and they need help in doing everything. But then, after seeing this video, I realized that if you tell them in a proper way, they will actually shine. So, these kids have showed us that if they can be
trained in a very good way, then not much difference could be there between normal kids and them. So, this was really an interesting thing that they did.” Another parent made a similar comment, “Yes, we now know that they also have the ability to do things. By knowing that they [children with disabilities] made this video, it makes us very happy!” Indeed, these children not only challenged assumptions about their own ‘capabilities,’ but also the capabilities of ‘children with disabilities.’ They motivated and instilled hope, among parents as well as health care providers, highlighting that change is possible. These attitudinal changes can be interpreted as both transformation at the individual, personal level, but also at a collective, social level.

Child co-researchers also positioned themselves as social actors, and as teachers, by sharing about community issues that needed to be addressed both for themselves as well as for the community at large. As well, they worked to break down dominant perceptions of what they can and cannot do and stirred others for action. A doctor on viewing the film shared,

“I am dumbfounded, as I do not know what to say. We are four doctors from the department of ophthalmology, and we found that in such a young age, each of you have already brought out so many social issues… You yourselves may not know how much you have taught us. Firstly, it is a great thing, at this age leaving aside your play, you have thoughtfully brought out your difficulties as well as your community’s social issues so beautifully. Secondly, you having the mind to share and bring out these issues is a very great thing. That to, being small children, capturing these videos and explaining the issues in detail, is a great thing. Before the society takes action to solve these issues, as doctors itself we have not thought about these issues from this angle. We are more than ready to offer any help that you may require from our end.”

A social worker shared how she was amazed by the amount of knowledge that child co-researchers had exhibited and said, “One thing I realized was that these children are aware of the mature issues that are happening in life with adults like alcohol, tobacco, and they have their own thing by sharing how the father beats the mother and why…”
Small immature and mature issues were shared. I have realized that even they know about all that because it is happening in their house. ... Their very agenda is ‘remove alcohol from Tamil Nadu!’

Moreover, child co-researchers also implicitly positioned themselves as resilient by highlighting how they were willing to overcome the everyday injustices they faced and address issues for the community at large. A social worker described how children with disabilities often started their lives with negative attitudes from the community and how they were able to acknowledge these negative experiences as well use it for addressing the same issues faced by many other children within their community, and additionally think about other shared community problems. She explained,

“In this society, from home, they start their life with criticisms. The way the people call children include ‘glasses’ for people with glasses, ‘crow’ for dark people and in a more derogatory way they also call some people ‘sissy’ and ‘cowards’. These words in and of itself will make them feel negative and stressed, and that too for children in such a young age. It creates emotional trauma. The reason why I teared up was because, it was out of joy and not out of fear, because these children in spite of all these troubles, they are concerned about the community. We thought that we can focus on the issues the children have faced, but they have surpassed that and spoken about how in their village there are issues of drinking, and fighting, and garbage. Them having so much concern for their community is something special. It created a sense of hope! Through this video they have taught us a lesson.”

Similarly, another social worker shared,

“You have already told us that you are fighting against all odds in society and in school, where you have said they tease you and bully you, you have shared all of that very clearly and everyone who watches this will feel it. By overcoming all these issues, you have shown and proven to us that you are still managing these issues, that’s a great thing, it is to be appreciated … You are thinking a lot about
society, and these issues to be addressed, your suggestion and ideas will definitely bring out a change, little by little, in society.”

6.4.3.2 Motivation to act among parents, service providers, and village leaders

In turn, parents, service providers, and community members articulated an enhanced motivation to act to address the issues of occupational injustices and exclusion of children with disabilities, and other concerns, within their community. The local health aide pointed to the collective responsibility in addressing issues faced by children with disabilities, and said,

“We have to go down and do it. If we stop in the middle, no change will happen. If we go down, try and keep motivating the community, then it will happen. All these five children surely made an impact, and their parents if they speak to ten other people, there will be more impact. We can, in turn, reach many more special children who are out there. We can bring out their special abilities. These five children are the key people, and through them we can do more!”

Parents of children with disabilities, after being sensitized to the everyday experiences of injustices their child faced, spoke about having an enhanced motivation to act. They expressed a shared responsibility in addressing the issues their children faced as well as other issues that were brought forward by them. A parent shared,

“The video that you have taken is very good. Only now can I understand your feeling. I can now know how you feel when you go to school. Inside the school, outside the school, and all the problems you are facing, you have expressed very well in the video. After seeing all this, we will also change. We have seen garbage only on the roads but not inside the wells and the fields. Now we have seen that through the video, and we need to try and rectify all these issues.”

Another parent stated, “I don’t know what to say, the children have done everything nicely. Now we know how to keep the place clean without throwing garbage, but now we
need to do it and try to keep our place and village clean.” This was reiterated by another parent, who said, “After seeing all this, we will also change.”

Additionally, service providers and community members were sensitized to several community problematics that they had not identified until they watched the video. With sensitization, indeed there was a motivation to act. The health aide, who is also a member of the same village pointed out,

“We have never thought that our village had this much garbage. The garbage vehicle comes and takes all the garbage and that is what I thought was happening… I thought that everything was well kept in the village. But you have showed the wells and fields with garbage, and I haven’t seen this much garbage. You have portrayed a lot of information about our village and its surroundings… We have to try our best to address these issues and change the situation. So, let’s see how we can move forward with that!”

A doctor also described how her thinking about disability was challenged through the video, and indicated she was pushed to think about next steps for addressing change. She shared,

“What really struck me was that this whole thing, everything, disability and the other social issues that they brought up, even inclusion, is a social issue within our setting … We are all ophthalmologists and we screen children for refractive errors and we give glasses, and we think, ‘oh, the work is done’ and I am just realizing the problems people would face to meet that challenge. And I think now the whole issue has to come from changing the mindset of children and adults. One way we could do it by having role models you know like film stars and actors who promote these sorts of things. Looks like bullying is not just for vision but it's for other things like being short as well, so including everyone is something we need to work on in our schools and in our homes.”

The village leaders were also pushed to think about how to mobilize change. One of the leaders shared, “So how can we stop this problem [garbage accumulation]? We need to
stop people from giving plastic bottles in the shop. Because they are giving and selling plastic bottles that is the reason why people are throwing them in the well.”

6.4.3.3 Proposed solutions for action

The child co-researchers were hopeful for change and proposed various solutions that attended to the situated nature of the issues. These solutions primarily encompassed three types of strategies: sensitization, community programs, and systemic changes.

6.4.3.3.1 Sensitization

Addressing issues related to occupational marginalization of children with disabilities within schools, child co-researchers emphasized using media to raise awareness and understanding of teachers and the general public regarding their perspectives and experiences. Karthi shared, “For creating change, we need to make teachers understand these issues properly, that they are beating students like this, and not including them to participate in events…We need to try and explain to them. It’s up to them to understand or not to understand. Not only the teachers, but even others generally.”

He also pointed to the power of sharing personal stories by saying, “We can show photos and narrate our stories behind it and show it to people, like with editing, showing situations that are hard. We need to capture it and show it to them. We can also draw pictures and show it to them.” Additionally, child co-researchers presented a need for other children as well as adult community members to understand the consequences and feelings associated with teasing and bullying through in-person meetings and visual disseminations (i.e., books, posters, and videos). Karthi shared, “They should understand how it feels if the same thing would happen to them. They themselves need to think about it.” As well, Shivam expressed “We need to tell them affectionately that they shouldn’t do this.” Additionally, extending to issues of community violence, children proposed ways to stimulate community members to think about why they do what they do, and Karthi shared, “We need to ask people, ‘why are you fighting?’ and say ‘don’t fight,” and Shivam added, “If fights are going on, how can our village be good?”
In addressing interrelated issues of substance abuse and garbage accumulation, child co-researchers again pointed to the need for sensitizing community members, including children, of environmental and community consequences. As Shivam put it, “We need to tell people that they shouldn’t drink… And what they have in their hands they should not throw on the ground.” He also pointed to other strategies addressing children and said, “We can go to schools and stick photos there that say don’t smoke and don’t drink…. “ As well, he pointed to how media could be used for this purpose by saying, “Share it on YouTube and tell people that they shouldn’t be doing this and it’s not good. We need to add our voices in it and tell them…."

6.4.3.3.2 Proposed community programs

In addition to sensitization efforts, child co-researchers proposed program initiatives that could be implemented within their schools and community. For issues of teasing and bullying, they suggested having bodyguards within schools and a phone number to be used by children for additional protection and help. They also called for educational programs encompassing simulation and training activities relating to garbage sorting. For example, Shivam described, “We need to show people how to sort garbage, what is recycled and what is not recycled… only some people do the sorting, everyone else just throws the garbage in the lake, and the well, and everywhere else.” Additionally, more garbage bins in the area were called for as none of the existing shops had garbage bins in their vicinity. For example, Sanjith pointed out, “We need to have a dustbin here beside this shop, now they need to go somewhere else for the dustbin.” Similarly, proposed programs for issues of deforestation included having plant-related competitions for community members to become more involved in intentionally growing more greenery within their village. As Sanjith explained, “We can have an artistic plant competition so people grow different plants at home and make their areas beautiful!” and Karthi added, “People who grow plants well, might get a monetary reimbursement.”

6.4.3.3.3 Proposed systemic changes

Child co-researchers also called for systemic changes in addressing issues of substance abuse and garbage disposal. Specifically, they called for the closing down of government-
run liquor shops. Sanjith claimed, “We should not have the Brandy shops… These shops need to be shut down and they shouldn’t be there in the first place.” Shivam also added, “The shops that do business with this by selling alcohol bottles, those stores need to be closed.” Furthermore, specifically addressing garbage issues, child co-researchers proposed working alongside the village councilor to clean existing spaces and to increase the frequency of the garbage vehicle’s visit to their community.

6.4.3.4 Personal transformation of child co-researchers

Upon reflecting on their experiences of participating in the project, through on-going dialogue and in the final phases of the project, child co-researchers described several types of personal transformation experienced. For instance, they highlighted the courage and self-confidence that they had further developed from being involved in this project, that is, to speak out openly, to stand up for their rights, and to address community issues.

As Karthi shared, “Before, none of us spoke that loudly or openly, but now we have gained some courage… We have the courage to tell people not to throw garbage when we see them, or not to cut trees. I have gained courage to speak up for things like this.”

Sanjith also shared, “First, I was scared [to speak out], but now it has all gone.”

Similarly, Shivam pointed out, “At the beginning, I didn’t speak this much to everyone.”

As well, a parent pointed to the courage her son had developed through this project and said, “Before he never used to mingle with other children much, but now he has become very bold and speaks boldly with the others. [name] is speaking very well now.”

Child co-researchers, through engaging in shared dialogue and discussions, learned more about the topics discussed within the scope of this project, as well as how they could go about addressing it. As Sanjith pointed out, “I learnt about teasing and bullying, and garbage. I learned that we shouldn’t hit anyone, and if someone hits another person, we need to tell our teachers.” Shivam also shared, “We should not do anything wrong; we only should do good. If people tease and bully, we should, hmmm, tell them ‘please do not tease or bully’ we need say it out.”

Additionally, child co-researchers also obtained skill sets in working cameras and a computer. Shivam shared, “You taught us how to edit, and cut, and put a movie together...
by adding music and video, changing colour, and other edits … I learned how to use the camera and also use the computer.” Parents also pointed to new technical skills their children had gained and an interest in exploring how digital equipment function, as a parent described, “Yes, now, when he comes back home, he takes all the wires and does mechanic work on his own.”

6.5 Discussion

Paulo Freire (1993) articulates, “attempting to liberate the oppressed without their reflective participation in the act of liberation is to treat them as objects which must be saved from a burning building” (p. 47). This participatory action research project aimed to involve children with disabilities as co-researchers and knowledge producers in explicating and addressing issues related to occupation they wanted changed through shared reflection and dialogue. It embodied a process of raising critical consciousness (Freire, 1993) among child co-researchers, as well as their extended community members, regarding the occupational injustices and community issues experienced by them and the ways these were situated within complex contextual forces.

Indeed, critical consciousness raising has been situated as essential in fighting against the “culture of silence” (Freire, 1993, p. 12) that individuals experiencing injustices are often ‘kept submerged’ within and where critical awareness is made impossible. As such, “ignorance and lethargy” (Freire, 1993, p. 12) are direct products of the economic, political, and social domination. Within this project, child co-researchers, parents, as well as service providers, individualized issues of occupational injustices experienced by children with disabilities through reciprocal blaming. However, through engaging in the process of shared dialogue, they were able to explicate the complex contextual nature of how such injustices were shaped. Additionally, child co-researchers, through shared reflection and dialogue, were able to generate an understanding about violence and physical environmental issues as not specifically individual problems but rather issues that needed systemic changes. Thereby, the proposed solutions by child co-researchers predominantly addressed systemic changes and actions that sought to further raise critical awareness among community members about the situatedness of the issues, so they also
had the space to reflect, and in turn, act on the contextually located issues of injustices within their communities.

Extending understandings on the situated nature of occupation and occupational justice, the findings from this analysis support a conceptualization of occupational choice as a socio-political rather than an individual phenomenon (Galvaan, 2015). For example, occupational choices of children and adults related to engaging in substance abuse and violence presented within this PAR, were situated as engrained within family and cultural practices passed down from adults to children, and informed by socio-economic inequalities prevalent within that context. In turn, engaging in substance abuse practices and violence were seen as “predictable occupational choices” (Galvaan, 2015, p. 46) for the young and old people of this community, and were situated as taken-for-granted ways of being even if considered as unacceptable within that context. Additionally, socio-politically shaped patterns of occupational choice of children with disabilities were positioned as further contributing to social inequalities (Galvaan, 2015). All parents of children involved within this project were from low-income backgrounds, and were disadvantaged in terms of lacking educational opportunities. In turn, they longed for their children to have better access to education as means to transform their situations of poverty. However, the socio-political systems often failed to create spaces for the full inclusion of children with disabilities in schools, which pushed children with disabilities within that context to drop out of school and, in turn, perpetuated the cycle of poverty that their families were nested within.

The findings from this PAR highlighted in detail issues that have been previously brought forth by adolescents with disabilities from an urban and rural Central Indian context (Gulati, Paterson, Medves, & Luce-Kapler, 2011) as well as an urban South Indian context (Kembhavi, 2009). Within this participatory thematic analysis, child co-researchers not only acknowledged similar issues, but also addressed them in-depth and situated them within existing contextual forces. For instance, adolescents with disabilities from Gulati and colleagues (2011) pointed to family members as a barrier to their leisure occupations. In this project, child co-researchers not only acknowledged this barrier, but also situated parental resistance within issues of violence that was prevalent within their
communities, and how parents limited their occupational possibilities, especially in leisure, as a means of protection. As another example, the teasing and bullying of children with disabilities especially during play was highlighted by adolescents in the project carried out by Gulati and colleagues (2011), and this exclusion in play was further reiterated in the project by Kembhavi (2009). The results from this PAR project further adds to this scholarship by not only acknowledging these experiences, but also explicating the contextual contributors as well as the emotional and occupational impacts teasing and bullying have on children experiencing this violence. Moreover, adolescents with disabilities from Gulati and colleagues’ (2011) project highlighted wanting to show their talents and position themselves as capable individuals in front of their community, which child co-researchers within the scope of this project did not explicitly articulate but rather demonstrated through the film that they created. Overall, the experiences of children with disabilities that have been explicated and presented within this PAR project reflect how disability experiences are diverse and contextually situated. Specifically, it adds to the understanding of the socio-cultural production of disability as well as its intersectional nature that is consistent with a critical disability lens (Devlin & Pothier, 2006; Meekosha & Shuttleworth, 2009).

Key factors shaping the occupational experiences of children with disabilities were related to the social construction of disability and their attributed disability identity (Phelan & Kinsella, 2014), which the children involved within this PAR did not explicitly take on. This absence of addressing disability within conversations with children with disabilities was also seen within Phelan and Kinsella’s (2014) work who had articulated that children with disabilities potentially focused on aspects that were similar to lives of other children. As such, within the South Indian context where this research was carried out, as highlighted by parents and service providers, there was an embedded cultural striving for normalcy. Parents took up various actions, inclusive of biomedical and traditional approaches to healing, as means to cure the impairment. Service providers involved within this project pointed to examples highlighting that children with disabilities were given burns or were forced to get a hole in one of their ears as means for cure. Indeed, these actions were aimed at ‘fixing’ the impairments of children with disabilities more often than embracing and nurturing their abilities. This PAR with
children with disabilities focused on understanding their everyday lives and not specifically their impairments, and in turn, children with disabilities were able to speak of the alternative identities that they embraced as social actors and active citizens of their community. However, the perceived reluctance seen among children with disabilities in embracing a disability identity highlights a contextual absence of embracing positive group differences (Vehmas & Watson, 2014) and reiterates a concern that Gibson, Teachman and Hamdani (2016) brought forward, how can we best “assist children in forming and maintaining positive disability identities?” (p. 85). To add, how might we work with the social context to facilitate this process? Indeed, this requires changes in socio-political and cultural ways of seeing the abilities of all people along a continuum, which reflects an anti-dualistic stance that works against dichotomizing constructs of ability and disability (Vehmas & Watson, 2014).

In relation to conducting research on occupation and disability outside of a Western, individualistic perspective, this PAR was carried out within a community that embodied a collectivist way of being and doing. In turn, child co-researchers preferred to carry out a group video project rather than work on individual videos. This collectivist way of being was also made apparent by adolescents with disabilities within Gulati and colleagues’ (2011) work who, “wanted to be known for their achievements and contribution to the group effort rather than be romanticized for individual performances” (p. 75). In turn, this collectivist way of life also informed what issues were brought out as problematic by child co-researchers, which were predominantly community issues rather than solely individual injustices. Additionally, disability related experiences of injustices that children shared were not as much about their independence and autonomy, but rather, their need for inclusion to participate in occupations alongside their peers. These unique perspectives highlight the value of occupation in society by reflecting what Ramugondo and Kronenberg (2015) pointed to as collective occupations, “that are engaged in by individuals, groups, communities, and/or societies in everyday contexts; these may reflect an intention towards social cohesion or dysfunction, and/or advancement of or aversion to a common good” (p. 10).
The findings of this PAR also illustrate the potential of a critical occupational lens (Njelesani et al., 2013), and an occupational process of participatory research (Crabtree, Wall, & Ohm, 2016), in identifying and deepening understanding of the production of everyday injustices. Child co-researchers were involved in numerous occupations (e.g., filmmaking, games) through this PAR process, as well as used an occupational lens in explicating issues within their lives and their community. As Townsend (2015) points out, with a critical occupational perspective, one becomes conscious of everyday doing, which creates an awakening of occupational consciousness and the hegemonic power relations shaping everyday life (Ramugondo, 2015). In turn, child co-researchers were able to explicate nuances related to occupations and occupational injustices prevalent in the Global South, where issues of justice were not predominantly framed as matters of individual choice and autonomy as within dominant Western views (Durocher, Rappolt, & Gibson, 2014; Laliberte Rudman & Dennhardt, 2008). Rather, occupational injustices were seen as embedded within contextual forces of power imbalances, poverty, systemic corruption, and a culture of silence that presented as a lack of awareness and accessible information (Farias et al., 2016; Freire, 1993).

Additionally, by using a critical occupational science lens (Laliberte Rudman, 2018; Njelesani et al., 2013), child co-researchers challenged dominant understandings on occupation that tend to positively link it to health and well-being (Kiepek, Phelan, & Magalhães, 2014). Specifically, occupations addressing violence, substance abuse, improper garbage disposal, and deforestation, were positioned as negatively affecting community occupations, inclusion, health, and well-being. As well, occupations were described as contributing to occupational degradation, defined as “occurring when restricted or forced participation in occupations routinely degrades land, water, air, and food to benefit some persons more than others” (Townsend, 2015, p. 395). In turn, child co-researchers called for occupational sustainability (Townsend, 2015) by proposing solutions that pointed to occupations that managed and restored the “health of land, water, air and food for everyone” (Townsend, 2015, p. 395). Overall, the child co-researchers highlighted non-sanctioned and damaging occupations that often remain silenced in occupational science (Kiepek, Beagan, Laliberte Rudman, & Phelan, 2018) and amplified the situatedness of occupation and occupational justice from perspectives...
in the majority world that have been marginalized within the discipline’s scholarship (Magalhães et al., 2019). These non-Western perspectives point to issues of occupational injustices as collective experiences rather than as issues of individual autonomy or choice.

Although economic, socio-cultural, and systemic forces shaping disability related experiences and issues of occupational injustices were highlighted within this analysis, gender forces remained unaddressed. Disability within an Indian context has been positioned as gendered, by being an additional burden to the existing situations of marginalization of girls and women (Mehrotra, 2006). However, gender related issues were not forefronted within this project as all child co-researchers were boys. This absence of girls with disabilities poses questions related to whether girls with disabilities were more hidden within households, as the consequences for a girl embodying a disability identity is positioned as worse when compared to boys. The village health aide pointed to how girls with disabilities, especially those who had attained puberty, needed to be ‘additionally protected’ within this context when compared to boys, and parents were scared to leave them alone anywhere without their supervision. Additionally, girls identified as having a ‘disability’ faced barriers for marriage prospects in the future which parents were cautious about. A special educator shared how a parent blamed her by saying “‘You [special educator] are the one who has done this by calling my child MR [mentally retarded] over and over again. In the future if she does not get married, I will call the police and put you in jail.’” Indeed, disability is only one axis of oppression (Devlin & Pothier, 2006), and the experiences of girls with disabilities from a rural, low-income, Indian context are unique and diverse from what has been explicated within this research.

Furthermore, the information addressed within this PAR predominantly encompassed perspectives of children with disabilities who had the means to communicate verbally. There was a lack of resources, such as hearing aids or communication devices, to more fully support the inclusion of children with communication impairments, which impacted the full enactment of equitable collaboration, a central tenet of PAR (Benjamin-Thomas, Corrado et al., 2018). Additionally, most child co-researchers within the scope of this
project were school-going children with disabilities, and their experiences of injustices were primarily situated within the school system which would be different for children with disabilities who did not have opportunities for attending school. Finally, most meetings and interviews within this project were carried out in Tamil, and there might have been some information lost during the process of translation to English (Temple & Young, 2004). However, the first author conducted all meetings, and was the one who led the translation process, so contextual information was preserved during the translation process.

Children with disabilities were positioned as co-researchers within this PAR, with a space for them to decide the topics of discussion relevant to everyday doing that they found problematic. However, I, the primary investigator, expected that child co-researchers would share issues of injustices that they had been facing at an individual level and not about community problematics; were these research expectations informed by my own assumptions regarding the position of children with disabilities in society? I acknowledged them to be social actors and active citizens in all my writing, however, why then did I presume that the outcomes of this research would encompass addressing issues of their occupational injustices rather than community issues? Indeed, many of my pre-understandings and assumptions about children with disabilities, their experiences, and their position in society, were, and continue to be, challenged and expanded through this work. As such, within PAR, personal transformation can also be part of the experience of academic researchers (Benjamin-Thomas, Corrado et al., 2018).

Change is a continuous process, and within PAR there is a commitment to doing more than the raising of awareness and critical consciousness as a “critical understanding of the situation of oppression does not yet liberate the oppressed. But the revelation is a step in the right direction” (Freire, 2014, p. 24). Critical researchers are called to act, and within the scope of this project, continuous efforts are being made by the local collaborating institution, already providing health care and developmental services in the context, as well as by the primary investigator to enact action plans proposed by children. Certainly, the transformation that is hoped for will not happen by chance (Freire, 1993), and continuous efforts are needed.
6.6 Conclusion

The purpose of this PAR project was to critically explore, and begin to address, occupational injustices experienced by children with disabilities and their extended communities from a rural context within the Global South. Through combined participatory and theoretical analyses, understandings of the complex, situated nature of occupational injustices as shaped and navigated within a context in the Global South was highlighted. The child co-researchers embraced an occupational perspective in explicating their everyday lives as well as engaged in occupations within the participatory filmmaking process, which supported them in identifying situations of everyday injustices and in mobilizing transformative efforts addressing such injustices. The ongoing nature of transformation reflected within this PAR re-iterates calls for occupation-based scholars to continually and intentionally work towards mobilizing transformative efforts.
6.7 References


Chapter 7

7 Synthesis and Discussion

I began this PhD journey four years ago with a keen interest in learning about research approaches for enacting social transformation. As a pediatric occupational therapist with practice experiences in India, I was particularly interested in working alongside children with disabilities from a rural Indian context to collaboratively explore and address occupational injustices (Townsend & Wilcock, 2004) they faced. Through my engagement with literature, I learned that the first-hand perspectives of children with disabilities from the Global South are rarely heard within research and transformative initiatives (Kembhavi & Wirz, 2009; Wickenden & Kembhavi-Tam, 2014). This dissertation is situated within this journey of exploration of occupational injustices experienced by children with disabilities in collaboration with them, and within the discipline of occupational science. Its key purpose was to enact an occupation-based transformative research project with children with disabilities as means to mobilize actions addressing their situations of occupational injustices. Specific objectives included: working alongside children with disabilities from a rural village in Southern India as co-researchers in exploring their first-hand perspectives about their lives pertaining to occupation; collaboratively explicating the situated nature of their occupations and experiences of occupational injustices; and working with children and community stakeholders in mobilizing change addressing occupational injustices.

The dissertation has been structured in an integrated manuscript style, along with introductory and conclusion chapters. All manuscript style papers are co-authored, in most instances by members of my dissertation supervisory committee and local co-investigators in India. For all papers, I am the lead author reflecting my role as the primary investigator with primary intellectual contribution to this work.

In this chapter, I conclude by highlighting the key insights achieved through this dissertation in relation to its purpose and objectives, and point to how this work contributes to occupational science scholarship. Following this, I discuss implications and future research directions, with respect to methodology, research, theoretical
developments within occupational science, and educational policies. I also attend to the quality considerations embodied within this dissertation and consider the strengths and boundaries of the participatory action research (PAR) process enacted. Finally, given the centrality of critical reflexivity to critically-informed transformative work (Farias, Laliberte Rudman, & Magalhães, 2016; Phelan & Kinsella, 2013; Strega & Brown, 2015), I end by considering aspects of my personal transformation through this work.

7.1 Key Insights in Relation to Dissertation Purpose and Objectives

This dissertation broadly sought to respond to the call for transformative occupation-based research (Farias & Laliberte Rudman, 2016; Farias et al., 2016; Hocking, 2012; Hocking & Whiteford, 2012; Laliberte Rudman, 2014; Laliberte Rudman et al., 2019) by working with children with disabilities from rural Southern India as co-researchers in exploring and addressing situations of occupational injustices within their rural context. More specifically, this work addresses, in part, calls for methodological expansions within occupational science (Bailliard, 2015; Laliberte Rudman, 2012; Magalhães, Farias, Rivas-Quarneti, Alvarez, & Malfitano, 2019) by utilizing participatory filmmaking as a research methodology to work towards inclusive research practices with children with disabilities (Benjamin-Thomas et al., under review). Additionally, diverse perspectives from children with disabilities, along with perspectives from their parents, service providers, and community members, facilitated situated understandings about the constructs of occupation, occupational justice, and disability. Moreover, this PAR with children with disabilities mobilized transformation at different levels. In particular, children with disabilities challenged the taken-for-granted negative assumptions about their positioning within society; they sensitized community members about the everyday injustices they faced as well as illuminated larger community concerns pertaining to occupation. In addition, various community initiatives encompassing further sensitization and community programs were proposed. As well, through this PAR process, child co-researchers and adult facilitators experienced personal transformation.

Within chapter one, the introduction, I introduced key terms used within this dissertation, and made transparent my critical paradigmatic values and relationship to this research
topic and research context. To better contextualize the PAR project with children with disabilities, I presented a literature review on disability and disability research within an Indian context, highlighting the critical theoretical frameworks informing this research, as well as introduced the research approach and methodological choice.

Chapter two, the first manuscript (Benjamin-Thomas & Laliberte Rudman, 2018), critically explored the uptake of the occupational justice framework (Townsend & Wilcock, 2004; Wilcock & Townsend, 2000) within research. This framework was focused on as it has been central to growing calls within occupational science for addressing global injustices pertaining to occupation (Hocking, 2012; Hocking & Whiteford, 2012; Laliberte Rudman et al., 2008). As well, it has emphasized intents to spur occupational therapists and scientists to address injustices pertaining to occupation (Durocher, Gibson, & Rappolt, 2014; Farias et al., 2016; Stadnyk, Townsend, & Wilcock, 2010). In particular, this manuscript provided a critical examination of how the occupational justice framework has been applied within research as means to gain insights on ways forward in working towards a world that is ‘occupationally just’ (Stadnyk et al., 2010). The key findings of this critical examination raised several concerns regarding limitations and boundaries related to how occupational justice has, thus far, been taken up in occupation-based scholarship. First, it was found that the occupational justice framework had predominantly been used to interpret research findings, with only a few studies using this framework to inform participatory or transformative research approaches. Second, situations of occupational injustices were often individualized, with about half of the reviewed research articles highlighting the socio-political production of such injustices. Third, there were absences and silences within the occupational justice research reviewed. Of specific relevance to this dissertation, most occupational justice research was carried out within contexts in the Global North and, in turn, tended to unproblematically take up conceptualizations of occupational injustices commensurate with a Western worldview.

On the basis of this analysis of research using the occupational justice framework, this manuscript contributed to occupational science scholarship by highlighting two key recommendations. First, it was recommended that PAR (Benjamin-Thomas, Corrado,
McGrath, Laliberte Rudman, & Hand, 2018) be utilized within occupational justice research so as to more fully embody the stated intent of this framework to inform social transformation towards more occupationally just societies (Stadnyk et al., 2010). This recommendation was in line with the views of Trentham and Cockburn (2005) who articulated that PAR is consistent with the principles of occupational justice, and Townsend and Whiteford (2005) who situated the occupational justice framework as a participatory framework. Additionally, this paper pointed to the need to broaden the conceptualization of occupational justice by incorporating diverse perspectives from the Global South. This recommendation aligns with a conceptualization of occupational justice as incorporating a justice of difference (Wilcock & Townsend, 2009) that acknowledges diverse realities on issues pertaining to occupation and occupational justice (Hammell, 2011; Hocking, 2012). To address these recommendations specifically within this thesis, a PAR process was implemented, and the occupational justice framework was used to elucidate understandings based within the experiences of children with disabilities from a rural village in the Global South. This thesis created a space for the perspectives of children with disabilities situated in low-income, rural communities in the Global South whose experiences of occupational injustices were shaped by contextual forces of poverty, violence, cultural beliefs and practices, and imbalanced power structures.

Chapter three, the second manuscript (Benjamin-Thomas, Laliberte Rudman, Cameron, & Batorowicz, 2018), emerged from a search for methodological ways to mobilize participatory and transformative research with children to address occupational injustices. This manuscript is situated as a response to calls within occupational science for methodological expansions that inform transformative directions (Farias & Laliberte Rudman, 2016; Laliberte Rudman, 2012). In particular this manuscript presents a critical methodological review of interdisciplinary research with children and youth that had utilized one of three participatory digital methodologies (i.e., digital storytelling, participatory videos/filmmaking and participatory geographic information systems). This critical examination of articles explored the potential use of these methodologies in relation to both the broad call for occupation-focused transformative scholarship and my
thesis objective, that is, to create space for diverse perspectives on occupational justice, specifically perspectives of children and youth.

This review highlighted strengths of all three methodologies as participatory methodologies in involving children and youth within research and action processes, as well as challenges and tensions related to power sharing. Overall, this manuscript contributes to the occupational science scholarship by pointing to directions forward in responding to disciplinary calls for methodological expansions that inform transformative directions, as well as highlighting the importance of supporting inclusive research practices. It also made apparent a dearth of participatory research with children with disabilities, which was of specific relevance to this dissertation as children with disabilities were involved as co-researchers within the PAR carried out. Additionally, one of the three methodologies addressed within this manuscript, specifically, participatory filmmaking, was taken up within this dissertation’s PAR project with children with disabilities.

Chapter four and chapter five, the third and fourth manuscripts (Benjamin-Thomas et al., under review; Benjamin-Thomas, Laliberte Rudman, & Gunaseelan, in preparation) provide a transparent account of the participatory filmmaking project with children with disabilities in rural Southern India. This detailed account of the process, highlighting different project phases, activities carried out within each phase, challenges faced, and strategies used, responds to an identified need for detailed research accounts to support further use of participatory and transformative methodologies in general, and with children of all abilities from diverse global contexts. Chapter four, in particular, introduces participatory filmmaking as an inclusive research approach with the potential to involve children with disabilities as co-researchers and collaborators in addressing social transformation. It provides an overview of how participatory filmmaking was utilized within the PAR project carried out within this dissertation. Chapter five specifically illustrates the importance of critical reflexivity in guiding ethically responsible research practices. It highlights how self and shared reflexivity among facilitators as well as child co-researchers helped navigate ethical tensions in the field, namely, tensions related to the authenticity of stories, navigating researcher’s voice.
within the filmmaking process, issues of safety and risk associated with sharing ‘truth’, issues of representation, and tensions associated with limits to immediate action. The work on critical reflexivity reinforces calls made by other scholars who position critical reflexivity as central to guiding socially and ethically responsible research (Guillemin & Gillam, 2004; Phelan & Kinsella, 2013).

Both these manuscripts contribute to methodological expansion within occupational science by demonstrating the utility of participatory filmmaking in the study of occupational injustices (Durocher et al., 2014) and by moving transformative research forward (Farias, Laliberte Rudman, Magalhães, & Gastaldo, 2017). As well, they highlight the potential of participatory filmmaking as a research methodology in guiding inclusive research with children with disabilities. These manuscripts describe practical ways forward for occupational science scholars in enacting participatory, transformative, and inclusive occupation-based research.

Chapter six, the fifth and final manuscript, presents findings of the PAR with children with disabilities that was analyzed through a participatory thematic analysis in collaboration with children with disabilities and through a theoretical analysis using the critical occupational science perspective (Laliberte Rudman, 2018; Njelesani, Gibson, Nixon, Cameron & Polatajko, 2013) and critical disability perspectives (Devlin & Pothier, 2006; Goodley 2013; Hosking, 2008; Meekosha & Shuttleworth, 2009). Specifically, this manuscript sought to expand conceptualizations of occupation, occupational injustices, and disability, from perspectives in the Global South, through explicating the first-hand experiences of children with disabilities, as well as perspectives from their parents, service providers, and other community members. The findings from the participatory thematic analysis highlighted individual and community issues pertaining to occupation and occupational injustices that were considered as problematic by child co-researchers, and addressed how they were situated within varied contextual forces. The theoretical analysis of perspectives, from child co-researchers and secondary participants, further situated highlighted issues within contextual conditions. Additionally, experiences of transformation addressed through this PAR as well as proposed ways forward in further mobilizing transformative efforts were presented.
This manuscript adds to the occupational science scholarship by presenting nuanced understandings on the situated nature of occupational injustices experienced by children with disabilities from a rural village in the Global South, illustrating how they are shaped and negotiated within complex economic, socio-cultural and systemic conditions. Additionally, the insights generated expand the figured world of occupation (Kiepek, Phelan, & Magalhães, 2014) by explicating understandings of occupations that are often silenced within our discipline’s scholarship (Kiepek, Beagan, Laliberte Rudman, & Phelan, 2018), such as, occupational issues of violence (Smith & Hilton, 2008; Twinley & Addidle, 2012), substance abuse (Helbig & McKay, 2003; Kiepek & Magalhães, 2011) and occupational degradation (Townsend, 2015). Furthermore, this manuscript responds to a need within disability scholarship for increasing heterogeneity in understandings of disability by adding nuanced understandings on disability-related experiences from the Global South (Meekosha, 2011; Wickenden & Kembhavi-Tam, 2014). Specifically, it highlights perspectives of children with disabilities that challenged the taken-for-granted assumptions regarding their position within society that situated them as ‘incapable’ and of ‘lower status’ (Anees, 2014; Singh & Ghai, 2009). Overall, this manuscript re-iterates the power of a critical occupational science perspective (Laliberte Rudman, 2018; Njelesani, Gibson, Nixon, Cameron & Polatajko, 2013) in exploring and addressing occupational injustices faced by individuals and collectives within global contexts. In particular, child co-researchers were able to identify and analyze the situatedness of everyday injustices (Townsend, 2015), and mobilize transformation, through engaging critically in conversations around occupations.

Taken as a whole, the chapters within this dissertation address the calls for methodological expansion within occupational science by creating spaces for diverse perspectives on the situated nature of occupation and occupational injustice (Bailliard, 2016; Farias et al., 2016; Galvaan, 2015; Hocking, 2012; Laliberte Rudman & Huot, 2013). This work expands beyond dominant Western, middle-class, Anglophonic, female, able-bodied, adult, perspectives that dominate occupational science scholarship (Hammell, 2011; Hocking, 2012; Kantartzis & Molineux, 2012; Magalhães et al., 2019; Pollard, Sakellariou, & Lawson-Porter, 2010) and further mobilizes the discipline’s
transformative agenda in addressing global situations of occupational injustices (Hocking & Whiteford, 2012).

7.2 Implications and Future Directions

Within this section, several implications of this dissertation are discussed as they pertain to methodology, research directions, theoretical developments, and educational policies. Within each section, future directions emerging from this work are proposed.

7.2.1 Methodological and research implications for occupational science

This work is an enactment of the call for occupation-based transformative research (Farias et al., 2016; Farias et al., 2019; Hocking & Whiteford, 2012; Laliberte Rudman et al., 2019). Transformative research, of which PAR is a variant, broadly encompasses a moral commitment to altering situations of injustices through working alongside collectives experiencing such injustices and exposing unequal power relations that create situations of privilege and injustices (Farias et al., 2019). The raising of critical consciousness (Freire, 1993) is a central component of transformative research, including PAR, where individuals learn about the situatedness of their realities and are mobilized to address forces perpetuating such realities when they shape injustices. Overall, this dissertation took up the argument that participatory methodologies need critical underpinning along with a commitment for enacting social transformation, and that these three elements are seen as embedded with each other and cannot be viewed as independent or utilized independently (Farias et al., 2017). For example, without grounding in a critical perspective, there is the potential even within PAR to reduce collective, socio-politically shaped, issues of injustices to individual attributes, which in turn, may lead to efforts of ‘fixing’ individuals rather than addressing systemic forces shaping such injustices (Farias et al., 2016). Additionally, a lack of commitment to enacting social transformation dilutes the promise of PAR to span the knowledge generation to action continuum (Benjamin-Thomas, Corrado et al., 2018).

This dissertation specifically demonstrates how a critical uptake of participatory methodologies can mobilize transformative agendas within occupational science. As
well, it highlights how a critical occupational science perspective supports the identification of the everyday injustices, experienced among collectives across global contexts, and enables situating these injustices within contextual features and power relations. Finally, this work also points to the potential of using an interdisciplinary lens within occupational science research, specifically integrating critical disability perspectives to support understanding of the situated nature of disability and occupational experiences of people with disabilities in ways that push beyond individualizing frames.

7.2.1.1 Critically informed participatory methodologies as means for enacting occupational science’s transformative potential

This dissertation demonstrates that critically informed participatory methodologies can be mobilized within occupational science to move towards enacting its transformative potential (Farias et al., 2019; Hartman, Mandich, Magalhães, & Orchard, 2011; Hocking, 2012; Huot & Laliberte Rudman, 2015). Specifically, this critically-informed PAR supported children with disabilities to be co-researchers in identifying contextual conditions that perpetuated situations of occupational injustices, as well as in mobilizing transformative efforts that focused beyond individual change. This work provides an illustration of how participatory methodologies can serve towards mobilizing the full intent of occupational justice to enact social transformation.

Additionally, this dissertation illustrates that critically-informed participatory methodologies can be mobilized to address the need for greater diversity within occupational science scholarship (Hammell, 2011; Hocking, 2012) by creating a space for perspectives seldom heard within the discipline’s scholarship. Within occupational science “childhood and adolescent perspectives on occupation are infrequent” (Hocking, 2012, p. 57), and there is a dearth of perspectives from people with disabilities, especially from collectives within the Global South (Hammell, 2011). This dissertation enacted calls for occupational scientists to engage with children of all abilities, from a context within the Global South, to contribute to expanded understandings of occupation. In particular, this research approach supported the involvement of children within disabilities as co-researchers in exploring and addressing situations of occupational injustices, which mobilized transformation across different levels encompassing the
individual, the social, as well as systemic structures. In particular, parents, community members, and service providers were sensitized about, and were motivated to act addressing, the issues of occupational injustices that children with disabilities faced and community concerns prevalent within that context. Additionally, child co-researchers had proposed programs at the community level (e.g., tree planting programs) as well as called for systemic changes (e.g., increasing the frequency of garbage vehicle visits), of which some are being implemented and others noted for future implementation. In turn, based on these outcomes from this project, occupational science scholars are urged to utilize participatory methodologies within research to facilitate incorporation of diverse perspectives from varied populations, including perspectives from children and youth of all abilities, regarding experiences of injustices pertaining to occupation, as means to facilitate transformation within global contexts.

Although this dissertation has proposed one avenue for methodological expansion in occupational science by introducing participatory digital methodologies, specifically participatory filmmaking, there were still barriers within the scope of this transformative work to fully including all children with varied abilities particularly in terms of communication impairments. In turn, occupation-based scholars are pushed to further the methodologic developments within our discipline to better include children with diverse abilities, within research and action processes (Teachman & Gibson, 2018; Teachman, McDonough, Macarthur, & Gibson, 2018). Even though limitations were faced in fully including all of the children within this project, the dissertation does illustrate that when given the space children with disabilities are able to challenge the taken-for-granted negative understandings about their capabilities and their positioning within society.

Fully embracing participatory methodologies in a manner that is aligned with its critical roots means realizing the on-going nature of such work, and being committed to engaging in critical reflexivity and enacting transformation (Benjamin-Thomas, Corrado et al., 2018). As presented within this dissertation, numerous challenges were encountered within this messy participatory process, as well as within on-going efforts to mobilize transformation on completion of the research phase. However, this dissertation also provides a reassurance of the promise of PAR and that transformation is possible even
with challenges encountered. Engaging in transformative work mandates the commitment to taking an active role in the change process (Potts & Brown, 2005). Indeed, transformation is an ongoing process which is obtained both as a means and an ends (Benjamin-Thomas, Corrado et al., 2018). This dissertation supports the call for scholars to continue to engage in mobilizing transformation post completion of the research phase, sharing with others the process of ongoing transformation, and engaging in critical reflexivity to address ethical dilemmas throughout the research and action processes (Benjamin-Thomas, Corrado et al., 2018; Guillemin & Gillam, 2004; Phelan & Kinsella, 2013).

Overall, PAR, as reflected through this work with children with disabilities, can be seen as an occupational process embodying a variety of occupations. In this project, the occupational process included occupations such as filmmaking, guided walks, discussions, and games. The children enjoyed the process they were involved in, they found it very meaningful and had articulated wanting further continual engagement by suggesting other ideas for exploration on completion of this project. This positioning of PAR as an occupational process has also been put forward by Crabtree and colleagues (2016) who reflected on a PAR carried out in a prison setting, and how the PAR process addressed situations of occupational deprivation among prison inmates. However, with the exception of Crabtree and colleagues (2016), there seems to be a dearth of literature within occupational science that speaks to PAR as an occupational process. Situating PAR as an occupational process would stimulate occupational scientists to further take up this research approach in their areas of work, which would create avenues to further the understandings on occupation and occupational justice. However, this focus on PAR as an occupational process would mandate its critical uptake, in a manner that moves beyond focusing on individual experiences to taking into consideration the socio-politically constructed roots of occupational injustices (Angell, 2014; Baiillery, 2016; Farias et al., 2016; Galvaan, 2015; Kinsella & Durocher, 2016; Laliberte Rudman, 2013). Within this dissertation, a critical perspective, combined with space for dialogue and co-learning, supported child co-researchers in not only highlighting their experiences of occupational injustices and community problematics related to occupation, but also in mobilizing actions addressing how these injustices were situated within complex layers
of contextual conditions encompassing economic, socio-political and cultural that were beyond the individual.

7.2.1.2 Interdisciplinary perspectives within occupational science

There have been calls within occupation-based scholarship for interdisciplinary collaborations in addressing issues of occupational justice (Benjamin-Thomas & Laliberte Rudman, 2018; Ikiugu & Pollard, 2015; Laliberte Rudman, 2014) as means to deepen understanding of the causes of injustices as well as expand on ways to address such injustices (Bailliard, 2016). Indeed, addressing everyday injustices is a shared vision across disciplinary boundaries (Bailliard, 2016) even if the term ‘occupational justice’ was proposed by occupational scientists (Townsend & Wilcock, 2004; Wilcock & Townsend, 2000). This dissertation is situated within occupational science and is informed by the critical occupational science perspective (Laliberte Rudman, 2018; Njelesani et al., 2013), as well as supported by critical disability perspectives (Devlin & Pothier, 2006; Goodley 2013; Hosking, 2008; Meekosha & Shuttleworth, 2009).

Although the critical occupational science perspective created avenues for participatory exploration of the situated nature of everyday doing and injustices that children with disabilities and their communities faced, critical disability perspectives strengthened this analysis. Critical disability perspectives were used to explore nuances related to the heterogeneous and situated nature of disability related experiences and injustices experienced by children with disabilities. As such, Hammell (2015) has argued that within occupation-based scholarship, disability has been looked at in individualized ways. In turn, taking up critical disability perspectives enabled a shifting to understanding and addressing disability as socially, politically, and cultural situated. For instance, taking up this perspective illustrated how the meaning of disability in the study context was shaped through cultural and religious influences, as well as biomedical understandings existing within health and rehabilitation services.

There have been critiques within critical disability scholarship regarding scholarly colonialism presented in the form of one-way transfer of ideas from the Global North to the South which embody theories and disability models not relevant in communities in
the majority world (Meekosha, 2011; Meekosha & Shuttleworth, 2009). In turn, this scholarly colonialism has been posited by disability scholars as needing to be challenged so theories on disability emerge also from the Global South through participatory and collaborative initiatives (Meekosha, 2011; Meekosha & Shuttleworth, 2009). In this dissertation, we attend to this call for bringing out diverse perspectives on disability from the Global South through a PAR with children with disabilities from a rural village in Southern India. This PAR process supported explication of disability related experiences within this context in the Global South. As one example, it illustrated that the imperative to ‘fix’ or normalize a child with a disability in this context was shaped within socio-cultural forces of stigma that extended to the family system, rather than solely from pressures associated with ableism. Additionally, through the absent voices of girls with disabilities within this PAR, the study raises concerns regarding the gendered nature of disability within this context and how a disability identity may cause further restrictions for girls to a greater extent than boys.

Critical disability perspectives support viewing of children with disabilities as social actors. While children and youth have been increasingly been recognized as social actors (O’Kane, 2002), children with disabilities may still remain unacknowledged as responsible social actors within particular contexts (Boyden & Levison, 2000). This dissertation supports calls for scholars within occupational science to position children of all abilities as co-researchers and as social actors in addressing social transformation. This call for recognizing children with disabilities as social actors relates to Paulo Freire’s assertion that “only power that springs from the weakness of the oppressed will be sufficiently strong to free both” (Freire, 1993, p. 26), In other words, transformation becomes possible through learning with children with disabilities about marginalization and injustices as a means to inform action. By further analyzing constructs of disability and occupations in a participatory fashion, innovative understandings on disability, emancipation, and social participation (Meekosha & Shuttleworth, 2009) related to everyday doing can emerge from the ‘bottom up’ and reframe the positioning of children with disabilities in society (Devlin & Pothier, 2006). Indeed, there are many ways of understanding disability related experiences which need to be continually adapted through methodological developments (Benjamin-Thomas et al., under review;
Teachman & Gibson, 2018) so diverse perspectives of children with disabilities, through cultural dialogue from varied global contexts, can shape disability narratives (Meekosha, 2011; Meekosha & Shuttleworth, 2009).

The combined critical occupational science and critical disability perspectives utilized within this dissertation sought to highlight nuances related to the heterogeneous experiences of children with disabilities, related to everyday doing, in collaboration with them. Their first-hand perspectives predominantly positioned situations of occupational injustices as collective issues that were shaped by contextual conditions informed by, poverty, gender, violence, culture, and belief systems. Additionally, occupational participation for children with disabilities was not seen as a priority within forces of poverty when basic resources were insufficient.

This work marks out various future avenues for participatory elucidation of the everyday experiences, and doing, of children with disabilities, situated within changing social relations and cultural meanings. First, given contemporary silences in occupational science, there is a need for continued exploration of contextually shaped experiences of violence, institutionalization, and issues of marginalization that children with disabilities from Southern contexts face. Additionally, there is a need to expand understandings of the resilience that children with disabilities embody, even when submerged within oppressive structures and systems, and their power to address transformation as active citizens and social actors. Indeed, the positioning of children with disabilities have changed over the years, in concert with increasing calls for participatory research with children with disabilities (Gray & Winter, 2011; Stafford, 2017; Wickenden & Kembhavi-Tam, 2014), so they can be involved as decision makers on matters affecting them (United Nations, 1989; United Nations Children’s Fund, 2007) and find spaces to reclaim their identities (Priestley, 1998). In this dissertation, children with disabilities, when being given the space, positioned themselves as responsible citizens by not only addressing ‘matters affecting them’ but also ‘matters affecting their communities.’ They shared their views about issues of deforestation, violence, substance abuse, and garbage disposal in addition to their everyday experiences of occupational marginalization.
Overall, the use of critical disability perspectives combined with a critical occupational perspective has facilitated nuanced understandings on the situated nature of occupation, disability and occupational justice. In turn, this work reiterates calls for occupational scientists to expand collaborations within and outside our discipline in addressing global injustices related to occupation (Ikiugu & Pollard, 2015; Bailliard, 2016; Laliberte Rudman, 2014; Ramugondo, 2015).

7.2.2 Implications for theoretical development within occupational science

With calls put forward by scholars for diverse understandings on occupation and occupational justice from global contexts (Benjamin-Thomas & Laliberte Rudman, 2018; Hammell, 2011; Hocking, 2012), this dissertation sought to work with children with disabilities from a community in the Global South in exploring and addressing situations of occupational injustices. The utilization of the occupational justice framework supported the explication of issues pertaining to occupational marginalization (Durocher et al., 2014; Stadnyk et al., 2010; Townsend & Wilcock, 2004) and occupational possibilities (Laliberte Rudman, 2010) of children with disabilities, occupational choice of children and adults within their community (Galvaan, 2015), and occupational degradation (Townsend, 2015), as situated within complex structures beyond the individual level. As well, the findings pointed out that the experiences of injustices were considered predominantly as collective issues rather than as individual issues of choice and autonomy (Bailliard, 2016; Laliberte Rudman & Dennhardt, 2008). These complex layers of socio-political, economic, and cultural conditions relevant to contexts within the Global South need to be increasingly highlighted within occupational science scholarship to challenge the individualistic nature of how occupational justice has been predominantly addressed thus far (Benjamin-Thomas & Laliberte Rudman, 2018; Farias et al., 2016; Malfitano, de Souza, Townsend, & Lopes, 2019).

Within this research, employing a critical perspective and a focus on everyday occupation supported child co-researchers and community members to question the socio-political influences on situations of occupational injustices. For instance, the occupational marginalization of children with disabilities within school contexts was situated as
informed by a lack of systemic resources such as training opportunities to support teachers in facilitating full inclusion. The occupational choices related to substance abuse practices by children as well as adults were situated as shaped by poverty as well as systemic conditions such as government-run businesses that facilitate easy access to locally made alcohol and drugs. Additionally, substance abuse practices, alongside issues of teasing and bullying, were positioned as informed by family and cultural occupational patterns, situated within situations of poverty and oppression, that were passed on from adults to children (Galvaan, 2015). These occupational choices were posited by child co-researchers as unacceptable, however, their common prevalence within this community also reflected an unquestioned persistence (Galvaan, 2015).

In turn, this dissertation points to a need for further theoretical development of occupational justice in relation to the construct of occupational consciousness (Ramugondo, 2012), defined as, “an ongoing awareness of the dynamics of hegemony, an appreciation of the role of personal and collective occupations of daily life in perpetuating hegemonic practices, and an appraisal of resultant consequences for individual and collective well-being” (p. 337). This construct emerged as relevant at the end of my analysis, as I began to realize that part of the transformation occurring involved enhanced awareness of the broader contextual factors shaping personal and collective occupations and impacting on well-being. Thus, I argue that occupational consciousness may be of particular utility within PAR addressing the occupational justice framework. Within this project, child co-researchers carried out an occupational analysis of their everyday experiences within the community, and they presented issues of injustices pertaining to occupation as a short film. On dissemination of the film and shared dialogue among the viewers of the film, there was another layer of shared analysis of the contextually situated nature of injustices. Specifically, parents, service providers, and community leaders were involved in the process of reflecting on and analyzing the causes and consequences of injustices the child co-researchers had highlighted, which informed sensitization as well as stirred an intent for collective action among community members. In turn, occupational scientists working towards enacting occupation-based transformative agendas are called to work towards facilitating a shared occupational consciousness among communities as means towards addressing everyday injustices,
given that: “an external approach to analyzing occupations of others cannot result in 
change. The onus for analysis of occupation and its impact on well-being lies within the 
individual or collectives themselves” (Ramugondo, 2012, p. 337).

Overall, the integration of occupation-based constructs (Ramugondo, 2015) such as 
occupational choice (Galvaan, 2015), occupational consciousness (Ramugondo, 2012, 
2015), occupational possibilities (Laliberte Rudman, 2010), and occupational degradation 
(Townsend, 2015) with the occupational justice framework (Townsend & Wilcock, 2004; 
Wilcock & Townsend, 2000) lays a foundation for further theorizing of occupational 
justice (Bailliard, 2016). These concepts guide ongoing dialogue within occupational 
science (Laliberte Rudman et al., 2008) and further understandings on how issues of 
occupational justice are informed by complex social conditions that perpetuate 
hegemonic power relations and shape what people can and cannot do (Galvaan, 2015; 
Ramugondo 2012, 2015).

7.2.3 Implications for educational policies

In this section I discuss some implications for educational policies within a rural Indian 
context. More specifically, the findings from this work highlight some of the systemic 
issues related to the ‘inclusion’ of children with disabilities within main-stream school 
systems within a rural Indian context. It points to gaps in educational policies that intend 
to facilitate the inclusion of children with disabilities within schools but fail to include 
them in a manner where they can fully participate in school-related activities. 
Specifically, child co-researchers pointed to their intentional exclusion by teachers in 
extra-curricular school activities as well as in classroom activities due to their perceived 
lack of ability. This notion of ‘inclusion’ that is often considered as a binary opposite of 
exclusion has been problematized by Teachman (2016) who argues that this over 
simplified understanding of inclusion can produce more harm than good. Additionally, 
Teachman (2016) calls for better conceptualization of inclusion by situating it as more 
than just a physical component. The findings of this dissertation suggest that physical 
inclusion without supports to fully include children with disabilities in all school-related 
activities can create occupational injustices in ways that actually exclude and marginalize 
them from participating within educational institutions. In turn, educational policies
addressing ‘inclusion’ have the potential to reproduce social divisions that they sought to address.

The results from this dissertation point to a need for policies on inclusion, within a rural Indian context, to be redefined so children with disabilities can be better included within diverse school-related activities. For educational policies in India to better address the systemic nature of injustices related to inclusion, the findings argue for shared dialogue among teachers, special educators, children, parents, and policy makers. Specifically, avenues for shared dialogue would facilitate understanding of the socio-political nature of challenges presented, work against the tendency to place blame onto various types of social actors, and guide changes beyond an individual focus. Additionally, the findings from this work that highlight systemic barriers to inclusion, such as the low teacher to student ratio and the lack of teacher training on how to facilitate inclusion, reflect that a multi-prong approach to addressing inclusion is necessary. For example, findings suggest that the training of teachers as important but not sufficient, as systemic structures pose barriers for trained teachers to work with children with disabilities, and in turn, challenges to inclusion cannot be fully addressed even if teachers were trained. Some other examples of systemic changes required within educational policies encompass changes in addressing the individualized nature of existing disability policies where the focus for services is on the child with an impairment and not so much on the context. This multi-prong approach would simultaneously address other aspects of the social environment that include training and sensitization as means to facilitate the full inclusion of children with disabilities within schools. This critically-informed approach to inclusion and educational policies within India can support the calls for “an educational movement in India with a clear philosophical direction” (Singal, 2005, p. 346).

Although ‘inclusion’ within schools predominantly refers to children with disabilities, a participatory approach to further the understanding on the concept of inclusion might address a dilemma that Singal (2005) has forwarded: “does inclusion have boundaries with regard to characteristic of children?” As such, many children within an Indian context, who may not be identified as children with disabilities, also experience exclusion in schools, which could be related to difference is class, caste, economic background,
linguistic groups and others (Jha, 2008). Indeed, within an Indian context, the understanding of inclusion is still nascent (Singal, 2005) and through embracing a participatory approach to policy development addressing issues of inclusion of children with disabilities many other intersecting issues of social inequality can also be simultaneously highlighted and addressed.

Overall, the implications, and proposed ways forward, from this dissertation highlight the utility of participatory and inclusive research in addressing issues faced by children with disabilities and extended community concerns. In the next section of this chapter, I speak to some quality considerations employed when carrying out this PAR with children with disabilities as well as in writing all manuscripts of this dissertation.

7.3 Quality Considerations

Varied conceptions of research ‘quality’ and ‘rigor’ are informed by paradigmatic values that guide research processes as a means to facilitate meaningful coherence (Ravenek & Laliberte Rudman, 2013; Tracy, 2010). In turn, the quality criteria used within this dissertation were largely informed by critical paradigmatic values (Crotty, 1998; Ponterotto, 2005). In this section, I first outline how sincerity was addressed as a quality consideration (Tracy, 2010) in writing all manuscripts and conducting the PAR project. Then, I highlight specific quality criteria that were addressed within the critically-informed PAR carried out in collaboration with children with disabilities, which broadly encompassed PAR’s central tenets of equitable collaboration and social transformation (Benjamin-Thomas, Corrado et al., 2018), as well as additional quality criteria in relation to use of visual research methodologies with children.

7.3.1 General quality consideration addressing sincerity

Qualitative researchers are urged to address ‘sincerity’ within the research process, which “is marked by honesty and transparency about the researcher’s biases, goals, and foibles as well as about how these played a role in the methods, joys, and mistakes of the research” (Tracy, 2010, p. 841). Addressing sincerity encompasses the practices of researcher reflexivity and transparency (Tracy, 2010).
Critical reflexivity has been situated as foundational to transformative research practices and is defined as an “approach to reflection that focuses primarily on the politics and ideologies embedded within research processes and within the self of the researcher” (Strega & Brown, 2015, p. 8). In turn, critical reflexivity was crucial when working on all manuscripts within this dissertation. In chapter two, the first manuscript (Benjamin-Thomas & Laliberte Rudman, 2018), I employed a critical interpretive synthesis (Dixon-Woods et al., 2006) to analyze how the occupational justice framework had been used in research. When carrying out the analysis, I constantly engaged in reflexivity to situate myself within this work, and the assumptions and pre-understandings I carried with me about the occupational justice framework through the process of writing reflexive notes. Additionally, shared reflexivity with my supervisor through regular discussions and dialogue further informed sincerity within the analysis of articles and generation of themes.

Similarly, chapter three, the second manuscript (Benjamin Thomas, Laliberte Rudman et al., 2018), was a critical methodological review of three participatory digital methodologies, that were utilized within projects across varied disciplines, exploring their potential for transformative research within occupational science. To facilitate the critical analysis process, my supervisor and I collaboratively designed a set of questions informed by the principles of PAR and occupational science (Cargo & Mercer, 2008; Farias et al., 2017; Frisby, Reid, Millar, & Hoeber, 2005; Grimwood, 2015; Hocking, 2012). These questions supported critical evaluation of strengths and tensions related to participation and transformation and how occupation was addressed in articles within this analysis. Again, I engaged in a process of self-reflexivity, through journaling, before I started working on this paper to explore my positionality within this work and my motivations for exploring the potential of participatory digital methodologies for transformative occupation-based research.

Furthermore, the importance of critical reflexivity in guiding ethically responsible research has been illustrated in the chapter five, the fourth manuscript (Benjamin-Thomas et al., in preparation) of this dissertation. More specifically, I have shared reflexive notes from my researcher journal as well as made transparent the shared reflexive dialogues
with my co-facilitator and child co-researchers in addressing challenges, supports, and
tensions within this process. This process of reflexivity supported me in enacting
sincerity within the research process (Tracy, 2010) and in addressing ethical tensions in
the field (Benjamin-Thomas et al., in preparation).

In addition to engaging in critical reflexivity, I embodied transparency by being honest
about the research process (Tracy, 2010). A transparent account of the PAR process is
described in chapter four, the third manuscript (Benjamin-Thomas et al., under review),
where I share details about the different phases within this research, the activities carried
out within each phase, challenges faced, as well as strategies used to address challenges. I
maintained notes throughout the process that allowed me to reflect on key decisions
made, the reasoning behind those decisions, important memories and emotions, as well as
realizations that occurred throughout the process. These notes were maintained from the
initiation of the collaboration to the on-going action phase of this work. Overall, self-
reflexivity as well as shared reflexive dialogues, with my co-facilitator and with child co-
researchers, played a central role in navigating and enacting ethics in practice (Guillemin
& Gillam, 2004).

7.3.2 Quality criteria addressing the participatory action research
approach

7.3.2.1 Promoting equitable collaboration

Within participatory methodologies, the research process is as important as the research
outcome (Gubrium, Harper, & Otañez, 2015). Research practices within the PAR with
children with disabilities embodied flexibility by incorporating adaptations to the process
based on cultural practices and children’s impairment specific needs. As well, child co-
researchers had the space to participate as much as they liked within the different phases
of the participatory filmmaking process. Another key competent of this participatory
process included the sharing and negotiation of power between facilitators and child co-
researchers. Power differentials between children and adults within this context were
inherent. My co-facilitator and I intentionally worked towards sharing and negotiating
power with child co-researchers by creating a space for them to make project related
decisions, such as choosing a methodology, identifying topics and content for the film, and as well on a daily basis, making decisions such as the meeting location and the snacks they wanted to eat. More details of this process are addressed in chapter four (Benjamin-Thomas et al., under review).

7.3.2.2 Addressing sustainable social transformation

In concert with critically-informed PAR, this research is located within the continuum of knowledge generation and action, and acknowledges research as “an ongoing community-building enterprise” (Potts & Brown, 2015, p. 37). To address this transformative agenda, this PAR project with children with disabilities embodies an ongoing action phase. While there are challenges to mobilizing action within this PAR, such as political barriers caused by local elections and challenges to regular communication across time zones with community stakeholders in India, there are many players in the action phase, including myself, who are committed to mobilizing transformation. Many proposed solutions from child co-researchers have been incorporated into existing programs of the local collaborating institution. For example, the social workers have included topics of teasing, bullying and marginalization within their health education programs. As well, other proposed solutions, such as planting of trees within the village and addressing issues of garbage, are still being discussed and addressed in collaboration with other organizations and community stakeholders in terms of future implementation. Overall, the action phase within this PAR is situated as an ongoing process with some actions being presently implemented and others seen as agendas for future implementation.

7.3.3 Visual research ethics and quality: Representation, confidentiality and identity

Child co-researchers were engaged in regular discussions with facilitators about research ethics in relation to confidentiality and identity within the participatory filmmaking process (Lomax, 2015; Wiles, Coffey, Robison, & Prosser, 2012). To address issues of representation, confidentiality, and identity, linked to issues of stigmatization of children with disabilities within the research context, the people in the participatory film created
by the child co-researchers were unidentifiable. Children were specifically provided with training on how to capture visuals without any identifying information, which included them capturing broad visual frames where faces were not clearly visible, capturing the backs of people so faces were not visible, or capturing specific objects that may be related to their topic of discussion (e.g., glasses for teasing). Once videos were captured in an unidentifiable manner, the group (facilitators and child co-researchers) watched the visuals and further engaged in shared reflexivity and dialogue, about how identity and confidentiality was maintained or not maintained within their visuals, which worked to address ethical tensions in the field (Benjamin-Thomas et al., in preparation).

Additionally, considering ethics related to the shaping of stories, my co-facilitator and I acknowledged our position of power in relation to shaping the film created by children (Gubrium, Hill, & Flicker, 2014). In turn, we paid reflexive attention to power imbalances during the research process to promote spaces for the authentic voices of children with disabilities to be heard (Benjamin-Thomas et al., in preparation).

7.4 Final Reflections: Strengths, Boundaries, and New Learnings

7.4.1 Strengths

There are several strengths of this dissertation. First, my relationship with the local collaborating institution, as an alumnus, supported avenues for collaboration with local co-investigators and with the community where this PAR was carried out. Additionally, my familiarity with the local language, culture, and the geographic context where this project was carried out supported relationship building with the child co-researchers as well as their extended community, which was an essential component of the PAR process. Furthermore, I spent eight months in India for this project, and this long period of time created opportunities for strengthening collaborations with the local institution, and for multiple meetings with the child co-researchers to build rapport, work alongside them in creating the participatory film, and in the dissemination of the video.

Another key strength within this work included the adoption of critical paradigmatic values (Crotty, 1998; Ponterotto, 2005), which was further supported by Freire’s work on
critical pedagogy (1993), the critical occupational science perspective (Laliberte Rudman, 2018; Njelesani et al., 2013), and critical disability perspectives (Devlin & Pothier, 2006; Goodley 2013; Hosking, 2008; Meekosha & Shuttleworth, 2009). These paradigmatic values and theoretical perspectives informed the uptake of a PAR approach and the unique methodology of participatory filmmaking (Benjamin-Thomas, Laliberte Rudman, et al., 2018; Gubrium & Harper, 2013; Mitchell, Milne & de Lange, 2012). This approach and methodology created avenues for children with disabilities to be co-researchers in exploring issues that they deemed as important and needing change. As well, the participatory filmmaking process within this PAR was seen as an enjoyable process by children. Furthermore, critical paradigmatic values informed the explication of research findings in a manner that challenged taken-for-granted norms and ways of doing and positioning in relation to children with disabilities, and in mobilizing transformative agendas addressing issues of occupational injustices faced by children with disabilities and their communities. In turn, this transformative work actively resisted marginalizing research practices and embodied the process of addressing equity and justice within research by working to include children with disabilities as co-researchers.

7.4.2 Boundaries

There were also many boundaries to this work associated with the homogeneity of gender among the children involved, as well as the realities of carrying out a PAR across global contexts and within the scope of a PhD project. First, the group of children involved in this project were all boys. Girls with disabilities were not identified within this village, by health care providers or community members, to be involved within this project. Additional perspectives from girls with disabilities could have generated insights into the gendered nature of the occupational experiences and injustices faced by children with disabilities (Meekosha & Shuttleworth, 2009). Indeed, disability has been situated as a gendered construct within the Indian context (Mehrotra, 2006) where girls with disabilities often experience multiple disadvantages (Meekosha & Shuttleworth, 2009).

There were also challenges to facilitating equitable participation of all children involved within this project (Benjamin-Thomas et al., in preparation). In particular, we faced challenges in creating the space for a child who had a speech and hearing impairment to
fully participate in all activities as his hearing aid was not working, written forms of communication were not successful, and sign language was not an option given lack of knowledge of the facilitators and the child involved in the research. Additionally, two children involved within this project were living within a residential institution for children with disabilities, and it was hard to get them to voluntarily participate alongside the other group of children when they were home for their summer vacation. They were scared to interact with the larger group and preferred to meet separately by their house. In turn, they were involved as a separate group and their perspectives were only marginally integrated within the participatory film created.

With regard to the generation and analysis of information, all interviews/group-meetings were conducted in Tamil, with the exception of a few meetings with secondary participants from the local collaborating institution which were conducted in English. Translation of information from Tamil to English was conducted by myself with help from a local retired teacher, from a neighbouring area in relation to the research context, who addressed my clarifications during translation. The translation of information from Tamil to English was to support the theoretical analysis process, which was carried out with the English transcripts, and for writing up the findings from this work. Although there may have been information lost within this process (Temple & Young, 2004), my consistent involvement in leading data collection as well as conducting the translation process, allowed for better contextualization of information during the theoretical analysis process. Indeed, translation itself is a situated act influenced by the translator, and as the primary researcher navigating both insider and outsider positions within the context where this research was carried out, I want to acknowledge that my interpretation of information would have been influenced by differences in understandings of concepts, words, and worldviews (Temple & Young, 2004).

Additionally, there have been numerous challenges in mobilizing the action phase. Although I am fully committed to action in collaboration with community stakeholders in the field, international geographical boundaries, with my physical location in Canada, further create barriers to such collaboration. Specifically, there have been challenges with scheduling regular meetings and discussions with stakeholders in the local institution in
regard to whether and to what extent action is being mobilized. Additionally, there have also been challenges to mobilizing local ownership and leadership. Although this PAR project was a collaborative effort, most project activities in the field were carried out by me. There were challenges related to the ownership of this work among local collaborators, which might have been influenced by this project being situated as a student project that often required independent work. Additionally, a lack of time for local collaborators, who were health care providers, to leave their scheduled clinical work for carrying out this research further posed barriers for collaboration and ownership. This lack of local ownership during the research phase has implications for the action phase. Although actions are being mobilized, by the local institution within their capacity, the responsibility for initiating action plans and mobilizing this phase is seen as predominantly my responsibility because it falls within the PAR project I carried out within the scope of my PhD thesis. I do acknowledge that the responsibility is also mine, however, I also hoped for others from the research team, and the community, to also take ownership and mobilize actions in their own creative ways. There are numerous stakeholders, including people from the local institution, community members, children, as well as local organizations, who have communicated interest in being involved in the action phase and in the projects that might emerge from this work, but who are also looking for established plans for action. By trying to navigate this challenge in mobilizing action, I have been internally motivated to utilize my experiences in social innovation and social entrepreneurship to initiate the programs that the children have called for and to work alongside community stakeholders in further mobilizing these programs. I believe that mobilizing the action phase is indeed acting responsibly to what the children have called for.

7.4.3 New learnings

I conclude my dissertation by briefly highlighting my learnings through this PhD journey. I entered this journey wanting to further my understanding about if and where research fits within efforts aimed at social justice and transformation. I learned about the different research paradigms and different theoretical perspectives (Crotty, 1998; Guba & Lincoln, 1994) during this PhD journey, which helped me position myself within the critical
research paradigm (Crotty, 1998; Ponterotto, 2005) that acknowledges research and action to be within the same continuum. This journey helped me realize that my passion for addressing issues of injustice, by working with local communities in global spaces, can be done through ‘research,’ but within an approach to inquiry that is critical, participatory, and transformative.

Additionally, the PAR process I engaged in within this dissertation has helped me understand the messy realities of carrying out PAR which may not always align with our expectations linked with the promises of PAR (Klocker, 2012). My rich experiences from the field helped me recognize some of my own unconscious and conscious pre-understandings and assumptions with regard to this process and outcomes. Specifically, regarding my collaborators and co-researchers, children with disabilities, I learned that while I explicitly considered children with disabilities as social actors and active citizens, I did not expect them to share about societal issues within the scope of this project. I unconsciously expected that the issues brought out would be their individual experiences of injustices and issues that they were facing at an individual level. These assumptions might have been informed by my exposure to literature on occupational justice from a predominantly Western world view, as well as my educational and everyday experiences living within a North American context for the last six years. In turn, when many discussions with children with disabilities within this project tended to focus on community issues, I was challenged by my thinking about whether it was okay for the project to take a trajectory that focused on issues that were beyond individual situations of occupational injustices. I had to reflect on the principles of PAR and what equitable collaboration looked like, and then rethink some of my expectations for this project. As Farias and colleagues (2017) state, “within transformative work, such assumptions and perspectives need to be continuously interrogated given that they may at times be at odds with the social justice goals and lens selected for a specific study” (p. 5). I had to renegotiate my own expectations within the scope of this work, and further untangle what equitable collaboration within a PAR process encompassed.

Additionally, being able to carry out a PAR within the scope of my PhD education further sensitized me to some incongruencies between academic culture and PAR values, such
as, expectations for a clear protocol prior to initiating any collaboration with children, or the language used within ethics applications that mandated the use of terms that denote power differentials (e.g., participants versus co-researchers). I had to constantly navigate these challenges with the support of my supervisor. These challenges urged me to think about alternate ways of approaching academic structures and procedures in ways that aligned with the central tenets of PAR but also adhered to academic expectations. For instance, in my thesis protocol I was able to present two different research plans based on the two methodology options that children could choose between. In turn, presenting a tentative research protocol created a space for children to make some key project-related decisions, but at the same time also worked with academic requirements for the PhD program.

Moreover, my understandings on what action encompasses within PAR are also being continually transformed. PAR is certainly a time consuming and messy process (Baum, MacDougall, & Smith, 2006), and it is indeed impossible to come full circle in obtaining ‘social transformation’ within the scope of a four-year PhD project (Klocker, 2012). I have learned that it is impossible to have a conclusion to the action process within or even outside of this PhD work. As such, action is seen as rippling circles, which is hard to measure in a tangible sense. Ideally, the goals for action would include different stakeholders, who have the power to mobilize change, to address these issues and solutions in their own creative way. This expanded understanding of what transformation entails has motivated me to continue working on mobilizing action in ways that I am able to.

### 7.5 Concluding Remarks

Overall, having this opportunity to carry out a PAR for my PhD work has been a personally transformative experience, and I am still learning everyday while engaging and reflecting on the information generated within this work, and when having conversations about this work with my colleagues. Indeed, this experience has pushed me to challenge taken-for-granted ways of doing research and being a student, and my learning will never end. I have learned to think outside the box, and I am immensely motivated to continue this journey towards addressing social transformation through
equitable collaboration with individuals and collectives experiencing injustices. A quote devised and shared by Karthi, Sanjith, and Shivam, three of the child co-researchers in this project, acts as a constant reminder in supporting me in my journey towards working for justice: “we need to change what is bad to good, and what is good needs to remain as good.”
7.6 References


Appendix A: Western University Health Sciences Research Ethics Board Approval

Date: 23 February 2018
To: Dr. Debbie Rudman

Project ID: 110912

Study Title: Working Towards Promoting the Occupational Participation of Children with Disabilities through Participatory Action Research

Application Type: HSREB Initial Application

Review Type: Delegated

Meeting Date / Full Board Reporting Date: 23/Feb/2018 14:30

REB Approval Expiry Date: 23/Feb/2019

Dear Dr. Debbie Rudman,

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

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No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,
Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Marcelo Kremenchutzky, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
Appendix B: Christian Medical College Ethics Institutional Review Board Approval

OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD (IRB)
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA

Ethics Committee Registration No: ECR/226/NS/7/2013 Re-Reg-2014 Issued under Rule 1220 of the Drugs & Cosmetics Rules 1945, Govt. of India

Dr. George Thomas, M.B.B.S., D. Orth., Ph.D., Chairperson, Ethics Committee
Dr. L. Jayaselan, M.Sc., Ph.D., FSMS, FRSS, Secretary, Research Committee
Prof. Keith Gomez, B.Sc., MA (S.W), M.Phil., Deputy Chairperson, Ethics Committee
Dr. Anna Benjamin Pulimood, M.B.B.S., M.D., Chairperson, Research Committee & Principal
Dr. Biju George, M.B.B.S., M.D., Deputy Chairperson, Secretary, Ethics Committee, IRB
Additional Vice-Principal (Research)

April 04, 2018

Ms. Tanya Elizabeth Benjamin,
PhD Student, Department of Health & Rehabilitation Sciences,
Western University, London, Ontario, Canada.

Sub: Fluid Research Grant: New Proposal
Working towards promoting the occupational participation of children with disabilities through participatory action research
Ms. Tanya Elizabeth Benjamin, PhD Student, Department of Health & Rehabilitation Sciences, Western University, London, Ontario, Canada & Dr. Vinod Joseph Abraham, Community Health, Dr. Debbie Laliberte Radman, Professor, School of Occupational Therapy, Western University, London, Ontario, Dr. Debra Cameron, Dissertation Committee Member, Assistant Professor, Department of Occupational Science and Occupational Therapy, University of Toronto, Ontario, Dr. Colleen McGrath, Dissertation Committee Member, Assistant Professor, School of Occupational Therapy, Western University, London Ontario, Mr. Jerome Dany, Praveen Raj, Mr. Samuel Prasanna Vinoth Kumar, Occupational Therapy Unit, Community Health

Ref: IRB: 11191 (OBSERVE) dated: 28.02.2018

Dear Ms. Tanya Elizabeth Benjamin,

The Institutional Review Board (Silver, Research and Ethics Committee) of the Christian Medical College, Vellore, reviewed and discussed your project titled “Working towards promoting the occupational participation of children with disabilities through participatory action research” on February 28th 2018.

The Committee reviewed the following documents:

1. IRB Application format
2. Information sheet and Informed Consent form
3. Children Assent Form
5. Western University Application.
6 Signature Page
7. No. of documents 1-6.
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<tr>
<td>Dr. George Thomas</td>
<td>MBBS, D Ortho, PhD</td>
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<td>Mr. Samuel Abraham</td>
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<td>BE, MS, PhD</td>
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<td>Dr. Prasanna Samuel</td>
<td>MSc, PhD</td>
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IRB: 11191 (OB servE) dated: 28.02.2018
OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD (IRB)
CHRISTIAN MEDICAL COLLEGE, VELLORE, INDIA

Dr. George Thomas, M.B.B.S., D. Ortho., Ph.D.,
Chairperson, Ethics Committee

Dr. L. Jayaseelan, M.Sc., Ph.D., FSMS, FSSE,
Secretary, Research Committee

Prof. Keith Gomez, B.Sc., M.A.S.W., M.Phil.,
Deputy Chairperson, Ethics Committee

Dr. Anna Benjamin Palimood, M.B.B.S., M.D., Ph.D.,
Chairperson, Research Committee & Principal

Dr. Biju George, M.B.B.S., M.D.,
Deputy Chairperson, Secretary, Ethics Committee, IRB
Additional Vice-Principal (Research)

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<td>Dr. Abhay Cahakembe</td>
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<td>Dr. Suceena Alexander</td>
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<td>Dr. Sathya Subramani</td>
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<td>Internal, Clinician</td>
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<td>Social Worker</td>
<td>Vellore</td>
<td>External, Lay Person</td>
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<td>Mrs. Ilavarsi Jesudoss</td>
<td>Professor, Head of Medical Surgical Specialty 3 and Deputy Nursing Superintendent</td>
<td>College of Nursing, CMC, Vellore</td>
<td>Internal, Nurse</td>
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We approve the project to be conducted as presented.

Kindly provide the total number of patients enrolled in your study and the total number of withdrawals for the study entitled: “Working towards promoting the occupational participation of children with disabilities through participatory action research” on a monthly basis. Please send copies of this to the Research Office (research@cmevellore.ac.in).

Yours sincerely,

[Signature]

Secretary (Ethics Committee)
Institutional Review Board.

IRB: 11191 (OBSERVE) dated: 28.02.2018
Appendix C: Recruitment Flyer English Version

Invitation to Participate in a Research Project

We are looking for volunteers to participate in a collaborative research project between CMC Vellore and Western University. In this type of research, the researchers and participants work together to carry out the research.

What is This Project About?
This project aims to work with children with disabilities to explore the activities they do and would like to do. It aims to inform community actions that support these children in doing activities that are meaningful to them.

Who is Eligible?
- Child aged 10-18 years
- Identified as experiencing a disability (physical, intellectual, psychosocial)
- Have cognitive skills to participate in the project
- Interested in using cameras

What is Involved?
Children with disabilities will participate in approximately 18-21 group meetings with other children with disabilities over the course of 6-8 months, where they will have group activities and discussions about the everyday activities they do or want to do within their communities.

Children will be given cameras to take videos and photos of their choice to support discussions in meetings, and to put together a brief story about their activities individually or as a group. They will be trained on camera use and in storytelling.

For more information about this research project or to volunteer for this research project please contact:

Tanya Benjamin, PhD student
PhD Supervisor: Dr. Debbie Laliberte Rudman
PhD Committee Member: Dr. Vinod Joseph Abraham

Version Date: 13/02/2018
Appendix D: Recruitment Flyer Tamil Version

Invitation to Participate in a Research Project

10 மாதங்கள் தொடர்ச்சியான கட்டணத்தில் குறிப்பிட்டு நோக்கப்பட்டதற்கு நிறைவு குறித்து தரும் வரையப்படுத்தப்பட்டால்.

திறந்தவர்கள் வாழ்வு?

10 மாதங்கள் தொடர்ச்சியான கட்டணத்தில் குறிப்பிட்டு நோக்கப்பட்டதற்கு நிறைவு குறித்து தரும் வரையப்படுத்தப்பட்டால்.

பாதுகாப்பு குறிப்பிட்டு வாழ்வு திறைய வேலையிலும்.

பாதுகாப்பு குறிப்பிட்டு வாழ்வு திறைய வேலையிலும்.


dr. Ph.D. பாதுகாப்பு வாழ்வு திறைய வேலையிலும்.

Ph.D. பாதுகாப்பு வாழ்வு திறைய வேலையிலும்.

Ph.D. பாதுகாப்பு வாழ்வு திறைய வேலையிலும்.

Ph.D. பாதுகாப்பு வாழ்வு திறைய வேலையிலும்.
Appendix E: English Letter of Information and Consent - Children with Disabilities as Primary Participants

Letter of Information and Consent Children with Disabilities as Participants

Project Title: Promoting the Occupational Participation of Children with Disabilities

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Researcher Background
I am a PhD student in the Department of Health and Rehabilitation Sciences, field of
Occupational Science at Western University. The information that is generated from this
project will be used in my thesis. I am an occupational therapist with previous experience of
working with children with disabilities in rural India.

Invitation to Participate
In this Consent document, “you” always refers to the study participant. If you are a substitute
decision maker, please remember that “you” refers to the study patient. If a substitute
decision maker is needed for this study, you will be asked to review and sign this consent
form on behalf of the participant.

You are being invited to participate in this research project as you are identified as
experiencing some form of disability and aged 10-18 years. This project aims to explore if
and how children with disabilities participate in occupations within the context of their daily
lives, with an intent to promote avenues to increase their occupational participation. In this
project, occupation is defined as the everyday activities that people do as individuals and
collectives.
This study will use a specific research process called participatory action research (PAR) and children with disabilities will be collaborators in: a) exploring if and how they participate in everyday occupations within the context of their daily lives; b) identifying supports and barriers related to their occupational participation; c) envisioning what they need and want in terms of participating in occupations at home and in the society; and d) working with community stakeholders towards addressing identified barriers and utilizing supports to promote their occupational participation. To address these objectives, children will first receive training on camera use, on obtaining de-identified photographs of people, and in collecting consent. Following which, children will be provided with cameras to take videos to convey their occupational experiences within group meetings with other children with disabilities, and produce a brief individual or collective story.

To participate in this study children, need to: a) be identified as experiencing disabilities (physical, intellectual or psychosocial); b) have cognitive skills to understand and participate in the research process; c) be 10-18 years of age; d) be able to communicate verbally or non-verbally with or without an assistive device; e) be interested in using a camera for sharing their experiences; f) residing within ____________ village; g) consent for group meetings to be audio recorded.

The purpose of this letter is to provide you with necessary information so you can make an informed decision about your participation within this research project. It is important for you to understand what participation in this study will involve. Please read the following information carefully and if there is anything that is not clear or if you would like more information, please contact the researcher using the details provided. Take the time to decide whether or not you wish for you to take part in this research project. If you decide to participate, you will have the option of giving verbal or written consent. A total of 6-9 children with disabilities will be recruited to participate in this research project. Thank you for reading this letter.

Why is this study being done?
There is very limited research with children with disabilities in India that provides avenues for listening to first-hand experiences of children with disabilities, as well as research that involves them as collaborators. The ability to participate in meaningful occupations can support child development, promote health and well-being and address their inclusion in society. This project seeks to involve children with disabilities as collaborators in choosing a specific topic related to their occupational participation that they would like to explore in order to work towards addressing the need for children with disabilities to participate in occupations within their community.

How long will you be in this study?
If you choose to take part in this study, you will be asked to take part in approximately 18-21 group meetings (2 hours long) with other children with disabilities over the course of the project that is for 6-8 months. There will be approximately 2-3 meetings in a week, and not every week will have meetings. You can leave the meeting when you want and be as involved as much as you would like.

What are the study procedures?
If you agree to participate within this research project, you will be involved in creating either an individual video that tells a story about your participation in occupation, or a video that the group develops to convey shared experiences of participation in occupation. Each meeting will involve enjoyable group activities that will be chosen based on your abilities, and will be followed by group discussions regarding your occupational participation (e.g., what activities you participate in, what barriers you face, what activities you would like to participate in, etc.) that will be facilitated based on the photos and videos you take and choose to be included within the videos you create. Prior to you using cameras, you will be trained on how to use digital equipment and on video making skills.

All meetings will occur in Tamil. All meetings will be audio-recorded, transcribed, and translated into English to explore ideas that emerge from these meetings regarding the experiences of children with disabilities within your community. All meetings will be held in an accessible location within your village and you will be provided with snacks during the meetings. If meetings happen in the neighboring village, then transportation will be arranged.

**What are the risks and harms of participating in this study?**
Occasionally some people can experience emotional discomfort when talking about situations of marginalization or exclusion within their communities. You are free to choose what to say and not to say, and can request to leave a meeting if and when discomfort or fatigue is experienced.

There may be some risks of identification of participants and community members within visuals (photos or videos). Children will have training on how to take photos and videos without the use of identifiable information (e.g., taking pictures of objects to represent a person versus the faces of people; blurring of images) and it will be established within the training that only de-identified visuals will be used within the context of this research project. In addition, we will obtain consent from children and community members for use and dissemination of the created digital narratives or video.

Within the context of group discussions people may say things that they do not want to be transmitted to others outside of the group, which can lead to a risk of privacy breach and issues related to confidentiality. Thus, at the beginning of each focus group, the facilitators will have a discussion regarding confidentiality and privacy, and ask participants not to discuss what is discussed in the group with people outside the group once the group is finished. Participants can control what they reveal/do not reveal about themselves within the context of group discussions.

Physical activities, if included as part of group activities, may present as a risk for children with disabilities. The facilitators will use professional expertise as occupational therapists to choose optimally safe activities based on needs of children involved within this project.

**What are the benefits of participating in this study?**
There are no direct benefits associated with your participation in this research project, however, you will be able to share experiences related to disability and the occupational participation of children with disabilities within that context. This information will play a key role in supporting action processes aimed at promoting avenues for occupational participation of children with disabilities. In addition, you will be able to interact with other
children with disabilities and do group activities tailored to your needs and abilities, and will also learn technical skill sets to work cameras and support video making processes.

**Can participants choose to leave the study?**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future. Information collected prior to withdrawal will be kept, unless you ask to have it removed from the study. You have the right to request withdrawal of information collected about you. If you wish to have your or your information removed, please let the researcher know. It may be challenging within a group discussion to remove one person’s contribution, but we will attempt to remove it. You do not have to be in this study if you do not wish to be. You do not have to answer questions in the meetings. You do not have to talk about anything in the meetings that you do not want to.

**How will participants’ information be kept confidential?**

Representatives of the University of Western Ontario Health Sciences Research Ethics Board may require access to your study-related records for monitoring purposes.

The group meetings will be audio-recorded. What you say will be typed out by a typist and translated into English, and all identifying information will be removed from these notes. The only people who will listen to the recordings will be members of the research team, the typist and translator. The only people who will read the meeting transcripts will be the research team.

The individual narratives/group video that will be created by you, based on your interests and after obtaining consent, will be shared with their community and in neighbouring communities through community meetings or in schools, in conference presentations, research publications and/or on the internet if decided by the children. To protect your confidentiality and confidentiality of community members, all videos will only have de-identified information, all identifiable information from photos and videos that will be included within narratives or the group video will be removed or de-identified (e.g., blurring).

To protect your identity and maintain confidentiality of information, a pseudonym or an identification number will be used instead of your name to identify recordings, notes, transcripts and meetings. You are free to request that parts of what you have said on the recording be erased, either during or after the group meetings. The consent form, notes and recordings will be locked in a secure place at Christian Medical College, and all information transferred into typied format and digital files will be de-identified and stored in a password protected and encrypted laptop. All information will be erased after 7 years, except for the de-identified videos created by the children.

While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report.
Quotes that you share during the meetings will be included in future publications and presentations and will be identified using fictional names. Personal details will be changed to ensure your anonymity.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of group meeting discussions prevents the researchers from guaranteeing complete confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the group meetings to others.

**Are participants compensated to be in this study?**
To thank you for your time and contributions to this project, all group meetings will have snacks and refreshments, along with fun activities during every meeting (e.g., group games) which will provide a space to interact with other children with disabilities and also work as a means to facilitate rapport building within the group. In addition, this project will also provide opportunities for skill building (e.g., working technology, building confidence and leadership skills). Moreover, if you need transportation for meetings held outside your village, the research facilitators will arrange transportation.

**What are the rights of participants?**
Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study, it will have no effect on your care. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form

**Whom do participants contact for questions?**
You will be given a copy of this letter of information and consent form once it has been signed. If you have any questions or want any additional information, you may contact Tanya Benjamin at [tbenjam4@uwo.ca](mailto:tbenjam4@uwo.ca) or by telephone at [_______________________].

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics at [ethics@uwo.ca](mailto:ethics@uwo.ca) or Christian Medical College, office of Research at [research@cmcvellore.ac.in](mailto:research@cmcvellore.ac.in). This letter is yours to keep for future reference.
Study Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,
Western University, London, Ontario
Email: [REDACTED]

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario
Email: [REDACTED]

Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health,
Christian Medical College, Bagayam,
Email: [REDACTED]

[ ] I confirm that I have read the Letter of Information and have had all questions answered to my satisfaction

[ ] I agree to participate in this research

[ ] I agree to be audio-recorded in this research

[ ] I agree for my contact information to be kept by the researcher for the purposes of sharing with me the final results of this project after completion

[ ] I consent to the use of de-identified quotes obtained during the study in the dissemination of this research

I also agree that any photos and videos taken by me during this project, as well as the digital narrative or participatory video created by me during this project, may be released for the following purposes:

1. In Articles: [ ]
2. In book chapters: [ ]
3. In conference presentations, slide or print form: [ ]
4. In a website on the internet [ ]

Version Date: 19/03/2018
5. In community meetings [ ]

<table>
<thead>
<tr>
<th>Print Name of Participant</th>
<th>Signature</th>
<th>Date (DD-MM-YYYY)</th>
</tr>
</thead>
</table>

My signature means that I have explained the study to the participant named above. I have answered all questions.

<table>
<thead>
<tr>
<th>Name of Person Obtaining Consent</th>
<th>Signature</th>
<th>Date (DD-MM-YYYY)</th>
</tr>
</thead>
</table>

[ ] Your signature on this form indicates that you are acting as a substitute decision maker for the participant and the study has been explained to you and all your questions have been answered to your satisfaction. You agree to allow the person you represent to take part in the study. You know that the person you represent can leave the study at any time.

<table>
<thead>
<tr>
<th>Name of Substitute Decision Maker</th>
<th>Signature</th>
<th>Date (DD-MM-YYYY)</th>
</tr>
</thead>
</table>

Relationship to Participant

[ ] The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

<table>
<thead>
<tr>
<th>Name of Witness</th>
<th>Signature</th>
<th>Date (DD-MM-YYYY)</th>
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</table>

Relationship to Participant
Appendix F: Tamil Letter of Information and Consent - Children with Disabilities as Primary Participants

Letter of information and consent – Children with Disabilities as Participants

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பொம்பு வருடம் 19.03.2018

பிற்புவர் சீசன் மாணவர்களைக் குறிப்பிட்டு, கூறியுள்ளன குறிப்பிட்டின் ஆரம்பத்திலிருந்து வரும் கூற்றுகளை படிக்கவுள்ளனர். முன்னைய பாடல் முழுக்கும் அகராதி அத்தகாலத்தில் குறிப்பிட்டின் ஆரம்பத்திலிருந்து வரும் கூற்றுகளை படிக்கவுள்ளனர். இதுவே பிற்புவர் சீசன் மாணவர்களுக்கு குறிப்பிட்டின் ஆரம்பத்திலிருந்து வரும் கூற்றுகளை படிக்கவுள்ளனர்.

a) கூற்று மாணவர் வாழ்வு மாணவர்களை படிக்கவுள்ளனர் படிக்கவுள்ளனர்.
b) தீட்சன் மாணவர்கள் செய்யும் கூறுகளை படிமுக படிமுக வேலைக்காற்றின் குறிப்பிட்டின் ஆரம்பத்திலிருந்து வரும் கூற்றுகளை படிக்கவுள்ளனர்.
c) தீட்சன் மாணவர்கள் வாழ்வு மாணவர்களை படிக்கவுள்ளனர் படிக்கவுள்ளனர்.
d) தீட்சன் மாணவர்கள் வாழ்வு மாணவர்களை படிக்கவுள்ளனர் படிக்கவுள்ளனர்.

பிற்புவர் சீசன் மாணவர்கள் படிக்கவுள்ளனர். அவர்களின் பைட்டு செய்யும் படிமுக படிமுக வேலைக்காற்றின் குறிப்பிட்டின் ஆரம்பத்திலிருந்து வரும் கூற்றுகளை படிக்கவுள்ளனர். பிற்புவர் சீசன் மாணவர்கள் வாழ்வு மாணவர்களை படிக்கவுள்ளனர் படிக்கவுள்ளனர். அவர்களின் பைட்டு செய்யும் படிமுக படிமுக வேலைக்காற்றின் குறிப்பிட்டின் ஆரம்பத்திலிருந்து வரும் கூற்றுகளை படிக்கவுள்ளனர்.
தொழில்கல்வி தொடர்பில் கூறும் பார்வை? சுருக்கமாக? வட்டாரத்துடன் குறிப்பிட்டு பலகையாளர்களுடன். மேலும் முன்னுரையில் எண்ணாள் கருத்துக்குறிகள் நிறுவியது. இது தொழில்கல்வியின் வருமானத்தின் எண்ணாள் கருத்துக்குறிகளின் மூலம் நூற்றுணி நூற்றுணைகள் முறையில் குறிப்பிட்டு பலகையாளர்களுடன் இணைந்து பலகையாளர்களுடன் கூறும் பார்வை? சுருக்கமாக? வட்டாரத்துடன் குறிப்பிட்டு பலகையாளர்களுடன். மேலும் முன்னுரையில் எண்ணாள் கருத்துக்குறிகள் நிறுவியது. இது தொழில்கல்வியின் வருமானத்தின் எண்ணாள் கருத்துக்குறிகளின் மூலம் நூற்றுணி நூற்றுணைகள் முறையில் குறிப்பிட்டு பலகையாளர்களுடன் இணைந்து பலகையாளர்களுடன் கூறும் பார்வை? சுருக்கமாக? வட்டாரத்துடன் குறிப்பிட்டு பலகையாளர்களுடன்.

நூற்றுணி தொழில்கல்வியின் வருமானத்தின் எண்ணாள் கருத்துக்குறிகள் நிறுவியது. இது தொழில்கல்வியின் வருமானத்தின் எண்ணாள் கருத்துக்குறிகளின் மூலம் நூற்றுணி நூற்றுணைகள் முறையில் குறிப்பிட்டு பலகையாளர்களுடன் இணைந்து பலகையாளர்களுடன் கூறும் பார்வை? சுருக்கமாக? வட்டாரத்துடன் குறிப்பிட்டு பலகையாளர்களுடன்.
நான் ஒரு குழுவினால் தொலைமுறைச் செலவேற்றி மற்றும் வழங்க்கும் முயற்சிகளை பாதுகாப்பான பணிகளை முடித்து வருகிறேன். செலவேற்றி பணிகளை குழுவினால் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றினரைச் செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன். இன்றைய நாளில் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன்.

முன்னேற்றம் ஆரம்பிப்பினுள் உள்ளது. அத்துடன் செலவேற்றி மற்றும் வழங்கும் முயற்சிகளை பாதுகாப்பான பணிகளை முடித்து வருகிறேன். செலவேற்றி பணிகளை குழுவினால் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன். இன்றைய நாளில் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன்.

முன்னேற்றம் ஆரம்பிப்பினுள் உள்ளது. அத்துடன் செலவேற்றி மற்றும் வழங்கும் முயற்சிகளை பாதுகாப்பான பணிகளை முடித்து வருகிறேன். செலவேற்றி பணிகளை குழுவினால் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன். இன்றைய நாளில் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன்.

முன்னேற்றம் ஆரம்பிப்பினுள் உள்ளது. அத்துடன் செலவேற்றி மற்றும் வழங்கும் முயற்சிகளை பாதுகாப்பான பணிகளை முடித்து வருகிறேன். செலவேற்றி பணிகளை குழுவினால் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன். இன்றைய நாளில் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன்.

முன்னேற்றம் ஆரம்பிப்பினுள் உள்ளது. அத்துடன் செலவேற்றி மற்றும் வழங்கும் முயற்சிகளை பாதுகாப்பான பணிகளை முடித்து வருகிறேன். செலவேற்றி பணிகளை குழுவினால் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன். இன்றைய நாளில் தொலைமுறைச் செலவேற்றிலும் தொடர்ந்து செலவேற்றிலும் பாதுகாப்பு செய்து வருகிறேன்.
தொன்றிடும் சிற்றியலாரியம் கூட்டம். அக்கதையின்றி எளிக்கத்தக்கு பேரின் நவீன வலைத்தகவு பிரதானமாகுள்ளது. பொருள்களின் கீழ் தொலைவுச் சேவைகள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது. பொருள்களின் விளக்கம் பொருள்கள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது.

புனிதவானாகங்கள் தன்னார் நம்பு பாதம்பத்த தகவரே? 

சீடர்கள் தாம்பர்கள் கந்து அக்கதையின்றி எளிக்கத்தக்கு பேரின் நவீன வலைத்தகவு பிரதானமாகுள்ளது. பொருள்களின் கீழ் தொலைவுச் சேவைகள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது. பொருள்களின் விளக்கம் பொருள்கள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது.

தொன்றிடும் சிற்றியலாரியம் கூட்டம். அக்கதையின்றி எளிக்கத்தக்கு பேரின் நவீன வலைத்தகவு பிரதானமாகுள்ளது. பொருள்களின் கீழ் தொலைவுச் சேவைகள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது. பொருள்களின் விளக்கம் பொருள்கள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது. 

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புனிதவானாகங்கள் தன்று நம்பு பாதம்பத்த தகவரே?

சீடர்கள் தாம்பர்கள் கந்து அக்கதையின்றி எளிக்கத்தக்கு பேரின் நவீன வலைத்தகவு பிரதானமாகுள்ளது. பொருள்களின் கீழ் தொலைவுச் சேவைகள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது. பொருள்களின் விளக்கம் பொருள்கள் ஒன்றுக்கொன்றிடும் நோக்கமாகுள்ளது.
நிலை மணக்குறியாக நிறக்காம் முக்கியமான, முன்னாள் நிறக்கும் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிறக்காம் மணக்குறியாக நிற�...
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[ ] BWônfºd LhåûWLs CkRj hPj\]

[ ] CkR BnÅp ùNnVlúTôá
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[ ] BWônfºd LhåûWLs CkRj hPj\]

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[ ] CkR BnÅp ùNnVlúTôá
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[ ] BWônfºd LhåûWLs CkRj hPj\]

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[ ] CkR BnÅp ùNnVlúTôá
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[ ] BWônfºd LhåûWLs CkRj hPj\]

[ ] CkR BnÅp ùNnVlúTôá
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[ ] BWônfºd LhåûWLs CkRj hPj\]

[ ] CkR BnÅp ùNnVlúTôá
d¸ú\]
சேருந்துக்கும் வெளிப்படையில் ஒன்று விழுக்கொண்டு பொருள்குப்பற்றுக் கூடிய புதுமை வேண்டும் வனிதத்துறையில் வழங்குவதற்கு ஒன்று நோக்குகள்

[ ] பொருள்குப்பற்றுக் கூடிய புதுமை வேண்டும் வனிதத்துறையில் வழங்குவதற்கு ஒன்று நோக்குகள்

பொருள்குப்பற்றுக் கூடிய புதுமை வேண்டும் வனிதத்துறையில் வழங்குவதற்கு ஒன்று நோக்குகள்.
Appendix G: English Letter of Information and Assent - Children with Disabilities

Christian Medical College, Vellore
Department of Community Health

Assent for Children with Disabilities

Study Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, Western University, London, Ontario
Dr. Debbie Laliberte Rudman, Western University, London, Ontario
Dr. Vinod Joseph Abraham, Christian Medical College, Bagayam, Vellore, Tamil Nadu

Why are you here?
The researchers want to tell you about a research project that will explore if and how children with disabilities participate in activities within their communities. Tanya Benjamin and some other researchers are doing this study.

Why are they doing this study?
They want to hear your first-hand experiences about some supports and barriers you face that influence if and how you participate in activities that are important for you and that you need and want to do. They want to work with you to increase opportunities for children with disabilities to participate in occupations that are meaningful to them.

Will there be any tests?
No, there will be no tests, and none of these activities will be on your school report card.

What will happen to you?
If you want to participate in this study, four things will happen to you:
1. You will be invited to 18-21 group meetings with other children with disabilities over the period of 6-8 months, where you will play games, as well as discuss your experiences about if and how you participate in activities within your community. All group meetings will be audio-recorded.
2. You will be provided with a training as a part of the group on how to use a digital camera to take photos and videos, and on some precautions related to taking photos and videos within the community.
3. You will get a digital camera to use temporarily during this project, so you can take pictures and videos of places, objects, and people to help you in better sharing your experiences with the group related to your participation in activities.
4. You will use your pictures and videos to create a story about your experiences to share with others.
What will happen to your videos?
You will receive a copy of the video you create and the researcher will also keep a copy of the video you create. The created video will be shared in community meetings or in schools, or on the internet, depending on where you would like the video to be shared. The researchers might use the videos or pictures from the videos in academic articles (magazines for adults and researchers), academic books (text books for adults and older students in college) and in academic presentations (presentations for teachers, therapists and researchers) if that is okay with you.

Will the study help you?
No, this study will not directly help you but through participating in this study you will be able to interact with other children with disabilities who share similar experiences like you and will learn how to use digital equipment. In addition, the information you share and the videos that you will create through this project will help in creating more opportunities for children with disabilities to participate in meaningful activities.

Do you have to be in the study?
No, you do not have to participate in this study if you do not want to. No one will be mad at you if you do not want to be involved. Even if you say yes, you can change your mind later and withdraw from the study at any time.

What if you have any questions?
You can ask questions any time, now or later. You can talk to Tanya, your parents, or any of the researchers.

[ ] Yes, I want to participate in this study.

Print Name of Participant  Age  Date  Signature

Signature of Person Obtaining Consent  Date

[ ] The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

Name of Witness  Signature  Date (DD-MM-YYYY)

Relationship to Participant

Version Date: 19/03/2018
Appendix H: Tamil Letter of Information and Assent - Children with Disabilities

Assent for Children with Disabilities

Dr. ब्राह्मणवर्मन वर्मेन. Ph.D., OT Reg (Ont.) तथा Dr. उदमा दक्षिणनाथ, Ph.D., OT Reg (Ont.) द्वारा आयोजित अस्सेंट मणीपुरम विश्वविद्यालय, नेतृत्वाधीन, बांग्ला भाषा में लिखी गई है।

मुद्रक दर्शन

किसी भी अस्सेंट के लिए, अंतर्क्रिया के दौरान, अस्सेंट की निर्देशन में शामिल होना होगा।

मुद्रक दर्शनातिरिक्त

किसी भी अस्सेंट के लिए, अंतर्क्रिया के दौरान, अस्सेंट की निर्देशन में शामिल होना होगा।

बांग्ला भाषा में लिखी गई है।

प्रकाशित दिनांक 19.03.2018
1) புத்துக் காலப்பொழிவின் தொகுதிகளை 18-21 ஆண்டுகளுக்கு அரசு அகழ்குள்ளுக்கு என்னுடைய சிற்றுருவாக்காக்கள். தமிழ் கலைக்கலைகள், கலாச்சார முறைகள் மற்றும் 8 முதல் 11 ஆண்டுகளுக்கும் முதல் 18-21 ஆண்டுகளுக்கு என்னுடைய சிற்றுருவாக்காக்கள். கொழுதுறைகள் என்னுடைய சிற்றுருவாக்காக்கள் பற்றிய சிற்றுருவாக்காக்கள் சிற்றுருவாக்காக்கள், பற்றிய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுருவாக்காக்கள் சிற்றுருவாக்காக்கள் சிற்றுருவாக்காக்கள் சிற்றுருவாக்காக்கள்.

2) பழக்கம் / சிற்றுருவாக்கு தொகுதிகளை பயிரில் பற்றிய சிற்றுருவாக்காக்கள். சில காபார்ஸ் செய்து செய்து பயிரில் பற்றிய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுருவாக்காக்கள், சில காபார்ஸ் செய்து செய்து பயிரில் பற்றிய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுருவாக்காக்கள், சில காபார்ஸ் செய்து செய்து பயிரில் பற்றிய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுருவாக்காக்கள், சில காபார்ஸ் செய்து செய்து பயிரில் பற்றிய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுரு

3) பழக்கம் / சிற்றுருவாக்கு தொகுதிகளை பயிரில் பற்றிய சிற்றுருவாக்காக்கள். சில காபார்ஸ் செய்து செய்து பயிரில் பற்றிய சிற்றுருவாக்காக்களைச் செய்யுடைய சிற்றுரு

4) கொழுதுறைகள் என்பன செய்யப்பட்டுள்ளன. / சிற்றுருவாக்காக்களை இழுத்துப் பயிரியாக சிற்றுருவாக்காக்களை பற்றிய சிற்றுருவாக்காக்களைப் பற்றிய சிற்றுரு

2. கொழுதுறைகள் பயிரிலுள்ள உயர் பொழிவு?

கொழுதுறை என்பது காலமுண்டு பயிரியாக சிற்றுருவாக்காக்களை அதிர்வுறுப்பு தொகுதிகள் பயிரியாக சிற்றுருவாக்காக்களை அதிர்வுறுப்பு தொகுதிகள் பயிரியாக சிற்றுருவாக்காக்களை அதிர்வுறுப்பு தொகுதிகள் பயிரியாக சிற்றுரு

3. கொழுதுறையில் பயியான பொழிவு?

சிற்றுருவாக்காக்களை வழிகாட்டு படிகமாக சிற்றுருவாக்காக்களை வழிகாட்டு படிகமாக சிற்றுரு

4. கொழுதுறையில் பயியான வழிகாட்டு?

சிற்றுருவாக்காக்களை வழிகாட்டு படிகமாக சிற்றுருவாக்காக்களை வழிகாட்டு படிகமாக சிற்றுரு

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பதிப்பு தேதை 19.03.2018
பாராட்டியாளரின் வேலை, எம்பாரிக்கு செற்று தொடர்புத்தொடர்

[ ] மாநில வலயாட்சிகள் வருடத்து வழங்காமல் பாராட்டியாளரின் செயல்முறை வாய்ந்த தீர்மானங்களை எடுத்துச் சங்கிலியாக வருடப் பாராட்டிக்கையாக வருத்துச் செய்யப்பட்டது.

போர்ட் பொறியாளரின் வேலை, எண்ணறுத்தொடர்

தீர்மானம் போர்ருப்பிட்சிகள் வருடத்து வழங்கப்பட்டது. மிகுதியான போர்த்துக்கான செயல்முறை வாய்ந்த தீர்மானங்களை எடுத்துச் சங்கிலியாக போர்ருப்பிட்சியின் வருடப் பாராட்டிக்கையாக வருத்துச் செய்யப்பட்டது.

சதுர்வீதாளரின் வேலை, எண்ணறுத்தொடர்

பாராட்டியாளரின் பொருள்
Appendix 1: English Letter of Information and Consent - Parents of Children with Disabilities

Letter of Information and Consent - Parents/Guardians as Participants

Project Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science, Western University, London, Ontario
Email: tbenjam4@uwo.ca

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario
Email: drudman@uwo.ca

Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health, Christian Medical College, Bagayam,
Email: vinodabraham@cmcvellore.ac.in

Researcher Background
I am a PhD student in the Department of Health and Rehabilitation Sciences, field of Occupational Science at Western University. The information that is generated from this project will be used in my thesis. I am an occupational therapist with previous experience of working with children with disabilities in rural India.

Invitation to Participate
You are being invited to participate in a research project as you are a parent of a child with disability. This project aims to explore if and how children with disabilities participate in occupations within the context of their daily lives, with an intent to promote avenues to increase their occupational participation. In this project, occupation is defined as the everyday activities that people do as individuals and collectives.

This study will use a specific research process called participatory action research (PAR) and children with disabilities will be collaborators in: a) exploring if and how they participate in everyday occupations within the context of their daily lives; b) identifying supports and barriers related to their occupational participation; c) envisioning what they need and want in terms of participating in occupations at home and in the society; and d) working with community stakeholders towards addressing identified barriers and utilizing supports to
promote their occupational participation. To address these objectives, children will first receive training on camera use, on obtaining de-identified photographs of people, and in collecting consent. Following which, children will be provided with cameras to take videos to convey their occupational experiences within group meetings with other children with disabilities, and produce a brief individual or collective story.

To participate in this study, you need to: a) be identified as a parent of child participating within this study; b) be interested in participating in group meetings with other parents. If you would prefer to participate in an individual interview, that option is also possible; c) consent for the meeting (or one-on-one interview) to be audio recorded.

The purpose of this letter is to provide you with necessary information so you can make an informed decision about your participation within this research project. It is important for you to understand what participation in this study will involve. Please read the following information carefully and if there is anything that is not clear or if you would like more information, please contact the researcher using the details provided. Take the time to decide whether or not you wish to take part in this research project. If you decide to participate, you will have the option of giving verbal or written consent. Thank you for reading this letter.

Why is this study being done?
There is very limited research with children with disabilities in India that provides avenues for listening to first-hand experiences of children with disabilities, as well as research that involves them as collaborators. The ability to participate in meaningful occupations can support child development, promote health and well-being and address their inclusion in society. This project seeks to involve children with disabilities as collaborators in choosing a specific topic related to their occupational participation that they would like to explore in order to work towards addressing the need for children with disabilities to participate in occupations within their community.

How long will you be in this study?
If you choose to take part in this study, you will be asked to participate in two group meetings (1-hour long) with other parents/guardians over the course of the project that is for 6-8 months. You can leave the meeting when you want and be as involved as much as you would like.

What are the study procedures?
If you agree to participate in this project, you will be asked to participate in two group meetings with other parents/guardians of children with disabilities. Each meeting will be one hour long and will be conducted in an accessible and convenient location. If you are not comfortable/willing to participate in a group meeting, you will be provided with an option to do a one-on-one interview. The first meeting will focus on seeking information about if and how your child has opportunities to participate in occupations within your community. The second focus group meeting will focus your thoughts regarding this research project that your child was involved in.

The meeting (or one-on-one interview if chosen) will be audio-recorded and transcribed and translated into English (if the meeting was conducted in Tamil) to explore ideas that emerge from this meeting regarding the research process involving children as collaborators.
What are the risks and harms of participating in this study?
Occasionally some people can experience emotional discomfort when talking about situations of marginalization or exclusion within their communities. You are free to choose what to say and not to say, and can request to leave a meeting if and when discomfort or fatigue is experienced.

Within the context of group discussions people may say things that they do not want to be transmitted to others outside of the group, which can lead to a risk of privacy breach and issues related to confidentiality. Thus, at the beginning of each focus group, the facilitators will have a discussion regarding confidentiality and privacy, and ask participants not to discuss what is discussed in the group with people outside the group once the group is finished. Participants can control what they reveal/do not reveal about themselves within the context of group discussions.

What are the benefits of participating in this study?
There are no direct benefits associated with your participation in this research project. The information you share might help address issues related to the occupational participation of children with disabilities within their communities. The information you share will be presented to others through publications and at conferences and meetings. Your identity will not be released in any publications or presentation. If you want, a copy of the study results can be forwarded to you at the completion of the study.

Can participants choose to leave the study?
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future. Information collected prior to withdrawal will be kept, unless you ask to have it removed from the study. You have the right to request withdrawal of information collected about you. If you wish to have your information removed, please let the researcher know. It may be challenging within a group discussion to remove one person’s contribution, but we will attempt to remove it. You do not have to be in this study if you do not wish to be. You do not have to answer questions in the meetings or in the interview. You do not have to talk about anything in the meetings, or in the interview, that you do not want to.

How will participants’ information be kept confidential?
Representatives of the University of Western Ontario Health Sciences Research Ethics Board may require access to your study-related records for monitoring purposes.

The group meetings (or one-on-one if chosen), will be audio-recorded. What you say will be typed out by a typist and translated into English, and all identifying information will be removed from these notes. The only people who will listen to the recordings will be members of the research team, the typist and translator. The only people who will read the meeting and interview transcripts will be the research team.

To protect your identity and maintain confidentiality of information, only an identification number will be used instead of your name to identify recordings, notes, transcripts, interviews and meetings. You are free to request that parts of what you have said on the
recording be erased, either during or after the group meetings/ interview session. The consent form, notes and recordings will be locked in a secure place at Christian Medical College, and all information transferred into typed format and digital files will be de-identified and stored in a password protected and encrypted laptop. All information will be erased after 7 years.

While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report.

Quotes that you share during the meetings and interview will be included in future publications and presentations and will be identified using fictional names. Personal details will be changed to ensure your anonymity.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of group meeting discussions prevents the researchers from guaranteeing complete confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the group meetings to others.

Are participants compensated to be in this study?
You will not be compensated to participate in this study. We will provide snacks and refreshments at the meeting.

What are the rights of participants?
Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you and your child have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study, it will have no effect on your employment or services received. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

Whom do participants contact for questions?
You will be given a copy of this letter of information and consent form once it has been signed. If you have any questions or want any additional information, you may contact Tanya Benjamin at [tbenjam4@uwo.ca](mailto:tbenjam4@uwo.ca) or by telephone at [_______].

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics +1 (519) 661-3036, email: [ethics@uwo.ca](mailto:ethics@uwo.ca) or Christian Medical College, office of Research at 0416-2284294, email: [research@cmcvellore.ac.in](mailto:research@cmcvellore.ac.in)

This letter is yours to keep for future reference.
Christian Medical College, Vellore
Department of Community Health

Consent - Parents/Guardians of Children with Disabilities: Parents as Participants

Study Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,
Western University, London, Ontario
Email: [email]

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario
Email: [email]

Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health,
Christian Medical College, Bagayam,

[ ] I confirm that I have read the Letter of Information and have had all questions answered to my satisfaction

[ ] I agree to participate in this research

[ ] I agree to be audio-recorded in this research

[ ] I agree for my contact information to be kept by the researcher for the purposes of sharing with me the final results of this project after completion

[ ] I consent to the use of de-identified quotes obtained during the study in the dissemination of this research

____________________  __________________  __________________
Print Name of Participant  Signature  Date (DD-MM-YYYY)

Version Date: 19/03/2018

Page 5 of 6
My signature means that I have explained the study to the participant named above. I have answered all questions.

Name of Person Obtaining Consent  Signature  Date (DD-MM-YYYY)

[ ] The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

Name of Witness  Signature  Date (DD-MM-YYYY)

Relationship to Participant
Appendix J: Tamil Letter of Information and Consent - Parents of Children with Disabilities

Letter of information and consent – Parents / Guardians as Participants

[Text in Tamil]

[Signature]
a) தொடர்பு மாற்றும் நிலை. கொண்டாட்டம் இருப்பிட்டு தொடர்பு மாற்றும் நிலை. 

b) தொடர்பு மாற்றும் நிலை. கொண்டாட்டம் இருப்பிட்டு தொடர்பு மாற்றும் நிலை. 

c) தொடர்பு மாற்றும் நிலை. கொண்டாட்டம் இருப்பிட்டு தொடர்பு மாற்றும் நிலை. 

d) தொடர்பு மாற்றும் நிலை. கொண்டாட்டம் இருப்பிட்டு தொடர்பு மாற்றும் நிலை.
தரும நூற்றாண்டு எளிதான் வாழ்க்கை?

குறிப்பிட்டும் ஏற்குறைகளை ஆராய்த்துக்கொள்ள எளிதானது. தொழில்முறையில் பேர் தெற்கார்களை முற்றும் எளியானது. பொருள் தொழில் வரைத்தோட்டம் போன்ற நூற்றாண்டுகளுக்கு ஈடுபட்டுள்ள பொருள்வைத்துப் பகுதிகள். தொழில்முறையில் பேர் தெற்கார்களை முற்றும் எளிதானது. வொட்டாங்களின் கோரிகளை எளிதானது. பொருள் தொழில் வரைத்தோட்டம் போன்ற நூற்றாண்டுகளுக்கு ஈடுபட்டுள்ள பொருள்வைத்துப் பகுதிகள். தொழில்முறையில் பேர் தெற்கார்களை முற்றும் எளிதானது. வொட்டாங்களின் கோரிகளை எளிதானது. பொருள் தொழில் வரைத்தோட்டம் போன்ற நூற்றாண்டுகளுக்கு ஈடுபட்டுள்ள பொருள்வைத்துப் பகுதிகள்.

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தினசரில் வயசு உரிய பணமும் யார் கொழியாது. யனை தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது. பொதுவாக வலுசொல்லும் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது. பொதுவாக வலுசொல்லும் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது.

நூற்றாண்டுகளுக்கு முன்னரிட்ட விளையாட்டின் வழிபாட்டின் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது. பொதுவாக வலுசொல்லும் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது.

நூற்றாண்டுகளுக்கு முன்னரிட்ட விளையாட்டின் வழிபாட்டின் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது. பொதுவாக வலுசொல்லும் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது.

பொதுவாக வலுசொல்லும் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது. யார் என்று கீழே எழுத்து வைக்கவென்றும் கூறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றிய பயன்பாட்டில் வளர்ப்பானது. பொதுவாக வலுசொல்லும் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது.

பொதுவாக வலுசொல்லும் குறுக்கு தொடர்பான முன்னேற்றத்தின் பின்னர் வழிபாட்டில் அவர்கள் கைப்பற்றி வளர்ப்பானது.
The document contains text in Tamil, which is a South Indian language. The text seems to be a formal communication or a report, possibly about some administrative or research-related matters. The content is not clearly legible due to the quality of the image, rendering it difficult to extract meaningful information. It includes contact information and mentions the office of human research ethics and the office of Research at CMC Vellore.
Consent – Parents / Guardians as Participants.

 vigil — parental/guardian consent / participation

Consent for Participation

This study involves assessing the effects of a computer-aided intervention to promote physical activity in children with autism spectrum disorder. The consent form is being provided in both English and Tamil. The study is approved by the University of Western Ontario Research Ethics Board. The study is conducted in collaboration with the Children's Hospital of Eastern Ontario and the University of Madras.

Date: 19.03.2018

[ ] Parents/Guardians

[ ] Staff Members

[ ] Students

[ ] Volunteers

[ ] Others

Signed: ____________________________

Date: ____________________________
<table>
<thead>
<tr>
<th>தயாரிப்பு நிலை</th>
<th>குறிப்பிட்டுணரும் நிலை</th>
<th>பொருள்</th>
</tr>
</thead>
</table>

பணிதிக்கப்பட்டுள்ள டக்கப்மொழி
Appendix K: English Letter of Information and Consent - Service Providers

Letter of Information and Consent - Service Provider

Project Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,
Western University, London, Ontario
Email
Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario
Email
Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health,
Christian Medical College, Bagayam,
Phone: +91 9443253772

Researcher Background
I am a PhD student in the Department of Health and Rehabilitation Sciences, field of
Occupational Science at Western University. The information that is generated from this
project will be used in my thesis. I am an occupational therapist with previous experience of
working with children with disabilities in rural India.

Invitation to Participate
You are being invited to participate in a research project as you are identified as a service
provider for children with disabilities. This project aims to explore if and how children with
disabilities participate in occupations within the context of their daily lives, with an intent to
promote avenues to increase their occupational participation. In this project, occupation is
defined as the everyday activities that people do as individuals and collectives.

This study will use a specific research process called participatory action research (PAR) and
children with disabilities will be collaborators in: a) exploring if and how they participate in
everyday occupations within the context of their daily lives; b) identifying supports and
barriers related to their occupational participation; c) envisioning what they need and want in
terms of participating in occupations at home and in the society; and, d) working with
community stakeholders towards addressing identified barriers and utilizing supports to
promote their occupational participation. To address these objectives, children will first
receive training on camera use, on obtaining de-identified photographs of people, and in collecting consent. Following which, children will be provided with cameras to take photos or videos to convey their occupational experiences within group meetings with other children with disabilities, and produce a brief individual or collective story.

To participate in this study, you need to: a) be identified as a service provider for children with disabilities within the context where this research is carried out; b) interested in participating in a group interview with other service providers. If you would prefer to participate in an individual interview, that option is also possible; c) consent for the meeting (or one-on-one interview) to be audio recorded.

The purpose of this letter is to provide you with necessary information so you can make an informed decision about your participation within this research project. It is important for you to understand what participation in this study will involve. Please read the following information carefully and if there is anything that is not clear or if you would like more information, please contact the researcher using the details provided. Take the time to decide whether or not you wish to take part in this research project. If you decide to participate, you will have the option of giving verbal or written consent. Thank you for reading this letter.

Why is this study being done?
There is very limited research with children with disabilities in India that provides avenues for listening to first-hand experiences of children with disabilities, as well as research that involves them as collaborators. The ability to participate in meaningful occupations can support child development, promote health and well-being and address their inclusion in society. This project seeks to involve children with disabilities as collaborators in choosing a specific topic related to their occupational participation that they would like to explore in order to work towards addressing the need for children with disabilities to participate in occupations within their community.

How long will you be in this study?
If you choose to take part in this study, you will be asked to take part in one group meeting (1-hour long) with other service providers over the course of the project that is for 6-8 months. You can leave the meeting when you want and be as involved as much as you would like.

What are the study procedures?
If you agree to participate in this project, you will be asked to participate in one focus-group meeting with other service providers. The meeting will be one hour long and will be conducted in an accessible and convenient location. If you are not comfortable/willing to participate in a group meeting, you will be provided with an option to do a one-on-one interview. Questions in either the group meeting or individual interview will focus on hearing about your roles within the community and your perspectives on the experiences of children with disabilities within the community.

The group meeting or one-on-one interview will be audio-recorded and transcribed and translated into English to explore ideas that emerge from this meeting regarding the experiences of children with disabilities within your community.
What are the risks and harms of participating in this study?
Within the context of a group discussion, people may say things that they do not want to be transmitted to others outside of the group, which can lead to a risk of privacy breach and issues related to confidentiality. Thus, at the beginning of each group meeting, the facilitators will have a discussion regarding confidentiality and privacy, and ask people not to discuss what is discussed in the group with people outside the group once the group is finished. Participants can control what they reveal/do not reveal about themselves within the context of group discussions.

What are the benefits of participating in this study?
There are no direct benefits associated with your participation in this research project. The information you share might help address issues related to the occupational participation of children with disabilities within their communities. The information you share will be presented to others through publications and at conferences and meetings. Your identity will not be released in any publications or presentation. If you want, a copy of the study results can be forwarded to you at the completion of the study.

Can participants choose to leave the study?
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future. Information collected prior to withdrawal will be kept, unless you ask to have it removed from the study. You have the right to request withdrawal of information collected about you. If you wish to have your information removed, please let the researcher know. It may be challenging within a group discussion to remove one person’s contribution, but we will attempt to remove it. You do not have to be in this study if you do not wish to be. You do not have to answer questions in the meeting or in the interview. You do not have to talk about anything in the meeting, or in the interview, that you do not want to.

How will participants’ information be kept confidential?
Representatives of the University of Western Ontario Health Sciences Research Ethics Board may require access to your study-related records for monitoring purposes.

The group meeting (or one-on-one interview if chosen) will be audio-recorded. What you say will be typed out by a typist and translated in English, and all identifying information will be removed from these notes. The only people who will listen to the recordings will be members of the research team and the typist and translator. The only people who will read the meeting and interview transcripts will be the research team.

To protect your identity and maintain confidentiality of information, only an identification number will be used instead of your name to identify recordings, notes and transcripts. You are free to request that parts of what you have said on the recording be erased, either during or after the group meeting (or interview session if chosen). The consent form, notes and recordings will be locked in a secure place at Christian Medical College, and all information transferred into typed format and digital files will be de-identified and stored in a password protected and encrypted laptop. All information will be erased after 7 years.
While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report.

Quotes that you share during the meeting or interview will be included in future publications and presentations and will be identified using fictional names. Personal details will be changed to ensure your anonymity.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of group discussions prevents the researchers from guaranteeing complete confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the group meeting to others.

**Are participants compensated to be in this study?**
You will not be compensated to participate in this study. We will provide snacks and refreshments at the meeting.

**What are the rights of participants?**
Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study, it will have no effect on your employment. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

**Whom do participants contact for questions?**
You will be given a copy of this letter of information and consent form once it has been signed. If you have any questions or want any additional information, you may contact Tanya Benjamin at tbenjam4@uwo.ca or by telephone at [redacted].

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics at +1 (519) 661-3036, email: ethics@uwo.ca or Christian Medical College, office of Research at 0416-2284294, email: research@cmcvellore.ac.in

This letter is yours to keep for future reference.
Study Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,
Western University, London, Ontario

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario

Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health,
Christian Medical College, Bagayam,

[ ] I confirm that I have read the Letter of Information and have had all questions answered to my satisfaction

[ ] I agree to participate in this research

[ ] I agree to be audio-recorded in this research

[ ] I agree for my contact information to be kept by the researcher for the purposes of sharing with me the final results of this project after completion

[ ] I consent to the use of de-identified quotes obtained during the study in the dissemination of this research

____________________________       ___________________       __________________
Name of Person Obtaining Consent      Signature      Date (DD-MM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Version Date: 19/03/2018
[ ] The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

Name of Witness       Signature       Date (DD-MM-YYYY)

Relationship to Participant
Appendix L: Tamil Letter of Information and Consent - Service Providers

Letter of Information and Consent – Service Provider

Date: 19.02.2018

[Unreadable text]

[Unreadable text]
a) நுழைவு பற்றிய தனியார் விளக்கத்தில் குறிப்பிட்டப்பட்டுள்ள நோக்கங்கள் அதிகமாக வேண்டிகள்.

b) தொடர்பு பராமரிப்புக் குறிப்பிட்டுள்ள இந்து பல்வேளா செயல்களைக் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள்.

c) முற்போன்று, நுழைவு பற்றிய தனியார் விளக்கத்தில் அடையாளத்தைக் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள்.

d) நுழைவு பற்றிய வேலைகளைக் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள்.

பின்பதிவு, நுழைவுப் பற்றி வேலைவன்று நோக்கங்களை கண்டுபிடிக்கும் விளக்கத்தில் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள். கீழே தைரியாக நோக்கங்களைக் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள்.

a) இவ்விதமான விளக்கத்தில் வரும் நோக்கங்களை அடையாளத்தைக் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள்.

b) முற்போன்று, நுழைவு பற்றிய விளக்கத்தில் வரும் நோக்கங்களை அடையாளத்தைக் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள்.

c) இவ்விதமான விளக்கத்தில் வரும் நோக்கங்களை அடையாளத்தைக் குறிப்பிட்டுள்ள நோக்கங்களை ஊடற்றி வேண்டிகள்.
3.28 டீ. வணக்கம். நிதியாருக்கு தவறுகளின் காரணமாக நீண்டச் சிக்கியைத் தீர்வு செய்துக்காட்டினார். தவற்றுக்கான தீர்வு உறுதியாகச் செய்திகள் காட்டுக்கு காட்டுக் படப்படுத்தி செய்திகள் காட்டுக் படப்படிகள் செய்திகள் காட்டுக்கு காட்டுக் படப்பட்டுக் காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்படுத்தி செய்திகள் காட்டுக்கு காட்டுக் படப்படிகள் செய்திகள் காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டு படப்படிகள் செய்திகள் காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக்கு காட்டு படப்படிகள் செய்திகள் காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டு படப்படிகள் செய்திகள் காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக்கு காட்டு படப்படிகள் செய்திகள் காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக்கு காட்டு படப்படிகள் செய்திகள் காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டுக்கு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டுக் படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டுக்கு காட்டு படப்பட்டு காட்டு படப்படைத் தீர்வு செய்துக்காட்டினார். 

என்று தெளிவாக நிறைந்து கெடாமல் தேவாரசால் கதை கொண்டு வேண்டியது. 

என்று தெளிவாக நிறைந்து கெடாமல் தேவாரசால் 

என்று தெளிவாக நிறைந்து கெடாமல் தேவாரசால்
தங்கள் கைலாசத்தில் ஒரு காரணமால் கலந்து யார்களையும் அழகாகக் காண்பிட்டுவித்தது. அண்மை கிடை முடியாது என்று கொண்டாடாமல் கேம்பர்ஸிலை காட்டியது.

தினகால தமிழ்நாட்டில் அனைத்து மண்டலங்கள் நூறு அழகு தூண்டுகின்றது. குறிப்பிட்டு நூறு அழகால் இருந்தும் வெள்ளையும். எனவே என்னை கொண்டுள்ள தீர்வுத்துணையாரும் இச்செய்திகளை நோக்கியும். உடையவர்கள் கேம்பர்ஸிலை கொண்டாட்டு பொறுப்பு கொண்டாட்டமைத்து கொண்டாட்டமைக்கை உண்டாகின்றது.

மாநிலத்திற்கு நலமாக கொண்டாட்ட எடுக்கப்பட்டு?

தமிழ்நாட்டில் ஒரு காரணமால் நலமாக கொண்டாட்ட எடுக்கப்பட்டு, தீர்வுத்துணையாரும் தீர்வுத்துணையாரின் புனைத்துணையார்களில் கிடைத்து காட்டியது. கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் முன் கொண்டாட்டமைக்கை முன்னிடுவது. புனைத்துணையாரின் காரணமால் கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. மறுப்பிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. மறுப்பிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. மறுப்பிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. மறுப்பிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. மறுப்பிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. மறுப்பிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. மறுப்பிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது. இவ்விடங்கிட்டு கேம்பர்ஸிலை கொண்டாட்டமைக்கை உயிரிடியும் பெற்றுக்கொண்டாட்டமைக்கை முன்னிடுவது.
The document contains text in both Tamil and English. The text in Tamil appears to be discussing research ethics, possibly referencing a specific individual or organization such as the office of human research ethics at a university or research institution. The English text includes contact information for the office of research ethics at a different institution.

The text is not fully legible or clear, but it seems to be a message or notice related to research ethics.
சுற்றுச்சூழலின் சேவைகளைத் தொடங்குவதற்குப் பகுதியைப் பற்றிய செயல்களை அடையலாம். 

பெரும்பான்மை சேவைகளைப் பற்றிய பெரும்பான்மை பகுதி சேவைகளைப் பற்றிய செயல்களை அடையலாம்.
நுழைவாய்வு அளவு

வழிமுறைத்துறை முனை

வும் விளக்காமை மற்றும் வலை

மபிக்கைச்சுருளிகள் மற்றும் வலை

புதுப்பு நாள் 19.02.2018
Appendix M: English Letter of Information and Consent - Research Volunteers

Letter of Information and Consent - Research Volunteers

Project Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
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Researcher Background
I am a PhD student in the Department of Health and Rehabilitation Sciences, field of
Occupational Science at Western University. The information that is generated from this
project will be used in my thesis. I am an occupational therapist with previous experience of
working with children with disabilities in rural India.

Invitation to Participate
You are being invited to participate in a research project as you are identified as a research
volunteer. This project aims to explore if and how children with disabilities participate in
occupations within the context of their daily lives, with an intent to promote avenues to
increase their occupational participation. In this project, occupation is defined as the
everyday activities that people do as individuals and collectives.

This study will use a specific research process called participatory action research (PAR) and
children with disabilities will be collaborators in: a) exploring if and how they participate in
everyday occupations within the context of their daily lives; b) identifying supports and
barriers related to their occupational participation; c) envisioning what they need and want in
terms of participating in occupations at home and in the society; and, d) working with
community stakeholders towards addressing identified barriers and utilizing supports to
promote their occupational participation. To address these objectives, children will first
receive training on camera use, on obtaining de-identified photographs of people, and in collecting consent. Following which, children will be provided with cameras to take photos or videos to convey their occupational experiences within group meetings with other children with disabilities, and produce a brief individual or collective story.

To participate in this study, you need to: a) be identified as a volunteer within this research project; b) have participated in training children with disabilities in technical or creative skills (e.g., operating digital equipment, storytelling, etc.); and c) interested in participating in a group interview with other volunteers. If you would prefer to participate in an individual interview, that option is also possible; d) consent for the meeting (or one-on-one interview) to be audio recorded.

The purpose of this letter is to provide you with necessary information so you can make an informed decision about your participation within this research project. It is important for you to understand what participation in this study will involve. Please read the following information carefully and if there is anything that is not clear or if you would like more information, please contact the researcher using the details provided. Take the time to decide whether or not you wish to take part in this research project. If you decide to participate, you will have the option of giving verbal or written consent. Thank you for reading this letter.

Why is this study being done?
There is very limited research with children with disabilities in India that provides avenues for listening to first-hand experiences of children with disabilities, as well as research that involves them as collaborators. The ability to participate in meaningful occupations can support child development, promote health and well-being and address their inclusion in society. This project seeks to involve children with disabilities as collaborators in choosing a specific topic related to their occupational participation that they would like to explore in order to work towards addressing the need for children with disabilities to participate in occupations within their community.

How long will you be in this study?
If you choose to take part in this study, you will be asked to take part in one group meeting (1-hour long) with other volunteers over the course of the project that is for 6-8 months. You can leave the meeting when you want and be as involved as much as you would like.

What are the study procedures?
If you agree to participate in this project, you will be asked to participate in one focus-group meeting with other volunteers. The meeting will be one hour long and will be conducted in an accessible and convenient location. If you are not comfortable/willing to participate in a group meeting, you will be provided with an option to do a one-on-one interview. The meeting will focus on your experiences of participating within this participatory action research process.

The meeting (or one-on-one interview if chosen) will be audio-recorded and transcribed and translated into English (if the meeting was conducted in Tamil) to explore ideas that emerge from this meeting regarding the research process involving children as collaborators.
What are the risks and harms of participating in this study?
Within the context of a group discussion, people may say things that they do not want to be transmitted to others outside of the group, which can lead to a risk of privacy breach and issues related to confidentiality. Thus, at the beginning of the group meeting, the facilitators will have a discussion regarding confidentiality and privacy, and ask people not to discuss what is discussed in the group with people outside the group once the group is finished. Participants can control what they reveal/do not reveal about themselves within the context of group discussions.

What are the benefits of participating in this study?
There are no direct benefits associated with your participation in this research project. The information you share might support other researchers in involving volunteers and children as collaborators in the research process. The information you share will be presented to others through publications and at conferences and meetings. Your identity will not be released in any publications or presentation. If you want, a copy of the study results can be forwarded to you at the completion of the study.

Can participants choose to leave the study?
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future. Information collected prior to withdrawal will be kept, unless you ask to have it removed from the study. You have the right to request withdrawal of information collected about you. If you wish to have your information removed, please let the researcher know. It may be challenging within a group discussion to remove one person’s contribution, but we will attempt to remove it. You do not have to be in this study if you do not wish to be. You do not have to answer questions in the meeting or in the interview. You do not have to talk about anything in the meeting, or in the interview, that you do not want to.

How will participants’ information be kept confidential?
Representatives of the University of Western Ontario Health Sciences Research Ethics Board may require access to your study-related records for monitoring purposes.

The group meeting (or one-on-one interview if chosen) will be audio-recorded. What you say will be typed out by a typist and if needed translated in English, and all identifying information will be removed from these notes. The only people who will listen to the recordings will be members of the research team and the typist and translator. The only people who will read the meeting and interview transcript will be the research team.

To protect your identity and maintain confidentiality of information, only an identification number will be used instead of your name to identify recordings, notes and transcripts. You are free to request that parts of what you have said on the recording be erased, either during or after the group meeting (or interview session if chosen). The consent form, notes and recordings will be locked in a secure place at Christian Medical College, and all information transferred into typed format and digital files will be de-identified and stored in a password protected and encrypted laptop. All information will be erased after 7 years.
While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report.

Quotes that you share during the meeting or interview will be included in future publications and presentations and will be identified using fictional names. Personal details will be changed to ensure your anonymity.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of group discussions prevents the researchers from guaranteeing complete confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the group meeting to others.

**Are participants compensated to be in this study?**

You will not be compensated to participate in this study. We will provide snacks and refreshments at the meeting.

**What are the rights of participants?**

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study, it will have no effect on your employment. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics +1 (519) 661-3036, email: ethics@uwo.ca or Christian Medical College, office of Research at 0416-2284294, email: research@cmcvellore.ac.in

This letter is yours to keep for future reference.
Christian Medical College, Vellore  
Department of Community Health  

Consent - Research Volunteers  

Study Title: Promoting the Occupational Participation of Children with Disabilities  

Researchers  
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator  
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,  
Western University, London, Ontario  

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor  
Professor, School of Occupational Therapy  
Western University, London, Ontario  

Dr. Vinod Joseph Abraham, Doctoral advisory committee member  
Professor, Department of Community Health,  
Christian Medical College, Bagayam, Tamil Nadu, India

[ ] I confirm that I have read the Letter of Information and have had all questions answered to  
my satisfaction

[ ] I agree to participate in this research

[ ] I agree to be audio-recorded in this research

[ ] I agree for my contact information to be kept by the researcher for the purposes of sharing with me the final results of this project after completion

[ ] I consent to the use of de-identified quotes obtained during the study in the dissemination of this research

____________________       __________________       __________________
Print Name of Participant     Signature        Date (DD-MM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

____________________________       __________________
Name of Person Obtaining Consent     Signature

Version Date: 19/03/2018

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Appendix N: Tamil Letter of Information and Consent - Research Volunteers

செயல்பாட்டிற்கு முந்தைய முன்னாளின் காலத்தில் அறிவிக்கல்

Letter of Information and Consent – Research Volunteers

Dear Research Volunteers,

This letter serves as a formal notification that you have been selected as a volunteer for our upcoming study. As a volunteer, you will be required to participate in various activities that involve collecting data related to your health and well-being. The information you provide will be used solely for research purposes and will be kept confidential.

We understand that your privacy is of utmost importance, and we assure you that your personal information will be protected under strict confidentiality guidelines. Your participation is completely voluntary, and you may withdraw at any time without any consequences.

Please review the consent form carefully before signing it. If you have any questions or concerns, please do not hesitate to contact us.

Thank you for your cooperation and support.

Sincerely,

[Signature]

[Name]

[Date]

[Contact Information]

[Researcher's Name]

[Researcher's Position]

[Institution]

[Address]

[Phone Number]

[Email Address]
a) கையடுக்குக் காலம் தவறு வேண்டுமென்று பொருளிட்டுகள் கூறுவதற்கு எதிருவது.

b) தொடர் குறுகியாகத் தொடர்விளக்கம். குறிப்பிட்டுப்பட்டு விளக்காகத்துக் கூறுவதற்கு எதிருவது.

c) ஒவ்வொரு குறுகியது பொருட்களில் என்று வேண்டுமென்று பொருட்களின் தொடர்விளக்கம்.

d) பொருட்களின் எண்ணிக்கையின் இறுதியில் பொருட்களில் என்று வேண்டுமென்று பொருட்களின் தொடர்விளக்கம். தொடர்விளக்கத்து என்று வேண்டுமென்று பொருட்களின் தொடர்விளக்கம். கூறுவதற்கு எதிருவது. பொருட்களின் எண்ணிக்கையின் இறுதியில் பொருட்களின் தொடர்விளக்கத்து என்று வேண்டுமென்று பொருட்களின் தொடர்விளக்கம். கூறுவதற்கு எதிருவது.

பின்னரும், பொருட்களின் எண்ணிக்கையின் இறுதியில் பொருட்களின் தொடர்விளக்கத்து என்று வேண்டுமென்று பொருட்களின் தொடர்விளக்கம்.

6. பொருட்களின் எண்ணிக்கையின் இறுதியில் பொருட்களின் தொடர்விளக்கத்து என்று வேண்டுமென்று பொருட்களின் தொடர்விளக்கம்.
புதிய முறையில் அல்பரேட்சு நடைமுறை, கணிஒலுத் தற்கொடைகள், செயல்பாடு அளவிகள் போன்றவற்றின் தொடர்பான நோக்கையுடைய தனிப்பு தமிழகத்தில் உள்ள தொழில்நுட்ப மற்றும் நூல்த்துறையில் நிறுவப்பட்டுள்ள வரையறைகளுக்கு அடுத்து தனித்துவமாக நூல்பாடு நடைபெற்றது. விளக்கத்துறையில் உள்ள நூல்த்துறைப் பொருள்கள்களின் வரையறைகள் நிறுவுகின்றன. எனவே நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது.

முன்னெடுத்து கூற்றுத் தகவல் அல்லது கருத்துற்றம்?

தொடர்ந்து தகவலைக் கூற்று விளக்கத்துறைகள் வரையறையின் தொடர்பான விளக்க நோக்கையுடைய தனிப்பு தமிழகத்தில் உள்ள தொழில்நுட்ப மற்றும் நூல்த்துறையில் நிறுவப்பட்டுள்ள வரையறைகளுக்கு அடுத்து தனித்துவமாக நூல்பாடு நடைபெற்றது. விளக்கத்துறையில் உள்ள நூல்த்துறைப் பொருள்கள்களின் வரையறைகள் நிறுவுகின்றன. எனவே நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது. நூல்பாடு நடைபெற்றது.
தமிழ் மொழியில் வேறுபட்ட பொருள்களையும் தமிழ் மொழியில் வேறுபட்ட பொருள்களையும் குறிப்பிட்டு பற்றிய தலைமையிட்டு செய்தியை வைக்கிறார்கள். அம்பாட் இருந்த தேசியத் தலைமையிட்டு தமிழ்நாட்டில் பெறுவது குறிப்பிட்டு செய்தியை வைக்கிறார்கள்.

toe, அச்சந்தவுக்குள் இளைய வேளையானது நடவடியும் வேறு நிலையும் வேறு. கிட்டத்தள்ள நூற்றாண்டு நூற்றாண்டு வேறு பரிந்துரையும் வேறு. தமிழ்நாட்டின் தலைமையிட்டு தமிழ்நாட்டில் பெறுவது குறிப்பிட்டு செய்தியை வைக்கிறார்கள்.

போட்டி மற்றும் தலைமையிட்டு வேறுபட்ட பொருள்களையும் குறிப்பிட்டு பற்றிய தலைமையிட்டு செய்தியை வைக்கிறார்கள்?

முன்னோடியாக போட்டி மற்றும் தலைமையிட்டு வேறுபட்ட பொருள்களையும் குறிப்பிட்டு செய்தியை வைக்கிறார்கள். தமிழ்நாட்டின் தலைமையிட்டு தமிழ்நாட்டில் பெறுவது குறிப்பிட்டு செய்தியை வைக்கிறார்கள்.
Télé Sôs 19.03.2018

The office of human research ethics: +1 (519) 661-3036, E.Mail: ethics@uwo.ca

The office of Research at CMC Vellore: +91-416-2262294, email: research@cmcvellore.ac.in
முறையுடைய தலைப்பு

முதலூற்றவர் அறிவியல் வல்லுனர் இலங்கை இளைஞர் துவக்கத்தில் வரும் வணங்கன நிறுவனத் தலைமை குறிப்பிட்டு.

முறையீட்டைண்டியல்

நாவல் வல்லின் நூற்றாண்டு, Ph.D., பெருமையும் OT Reg (Ont.) குற்றங்களை குறிப்பிட்டு பார்க்கும் செயலங்கள் மேற்படுத்தி வேளாண்டாமல் தீர்க்கிறது. தீர்மானம் செய்து குறிப்பிட்டு தொடர்பு கொண்டாடவும். குழுக்கார், குழு செயலாக்கிய, பரிசாக நிறுவனம்: முறையீட்டு

பண்டை. வெளியில் வல்லின் நூற்றாண்டு, Ph.D., OT Reg (Ont.) குற்றங்களை மேற்படுத்தி வேளாண்டாமல் தீர்க்கிறது. தீர்மானம் செய்து குறிப்பிட்டு தொடர்பு கொண்டாடவும். குழுக்கார், குழு செயலாக்கிய, பரிசாக நிறுவனம்: முறையீட்டு—

முறையீட்டுரையில் வல்லின் வருமாறு மேற்படுத்தும் வேளாண்டாமல் தீர்மானம் செய்து குறிப்பிட்டு தொடர்பு கொண்டாடவும்.

பண்டையுடைய வல்லின் வருமாறு மேற்படுத்தும் வேளாண்டாமல் தீர்மானம் செய்து குறிப்பிட்டு தொடர்பு கொண்டாடவும்.

பண்டையுடைய வல்லின் வருமாறு மேற்படுத்தும் வேளாண்டாமல் தீர்மானம் செய்து குறிப்பிட்டு தொடர்பு கொண்டாடவும்.
Appendix O: English Letter of Information and Consent - Community Members Viewing the Video

Christian Medical College, Vellore
Department of Community Health

Letter of Information and Consent - Community Members/Stakeholders Viewing the Created Videos

Project Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,
Western University, London, Ontario

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario

Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health,
Christian Medical College, Bagayam,

Researcher Background
I am a PhD student in the Department of Health and Rehabilitation Sciences, field of
Occupational Science at Western University. The information that is generated from this
project will be used in my thesis. I am an occupational therapist with previous experience of
working with children with disabilities in rural India.

Invitation to Participate
You are being invited to participate in a research project as you are a member of society. This
project aims to explore if and how children with disabilities participate in occupations within
the context of their daily lives, with an intent to promote avenues to increase their
occupational participation. In this project, occupation is defined as the everyday activities
that people do as individuals and collectives.

This study will use a specific research process called participatory action research (PAR) and
children with disabilities will be collaborators in: a) exploring if and how they participate in
everyday occupations within the context of their daily lives; b) identifying supports and
barriers related to their occupational participation; c) envisioning what they need and want in
terms of participating in occupations at home and in the society; and, d) working with

Version Date: 19/03/2018
community stakeholders towards addressing identified barriers and utilizing supports to promote their occupational participation. To address these objectives, children will first receive training on camera use, on obtaining de-identified photographs of people, and in collecting consent. Following which, after being trained on camera use and ethics, children will be provided with cameras to take photos or videos to convey their occupational experiences within group meetings with other children with disabilities, and produce a brief individual or collective story.

To participate in this study, you need to: a) be invited to attend a community meeting where the videos created by children with disabilities will be shared; b) interested in participating in a group discussion during the community meeting; c) consent for the meeting to be audio recorded.

The purpose of this letter is to provide you with necessary information so you can make an informed decision about your participation within this research project. It is important for you to understand what participation in this study will involve. Please read the following information carefully and if there is anything that is not clear or if you would like more information, please contact the researcher using the details provided. Take the time to decide whether or not you wish to take part in this research project. If you decide to participate, you will have the option of giving verbal or written consent. If you are a child (18 years of age or younger), your parent/guardian must consent on your behalf, and you must provide an assent to participating. Thank you for reading this letter.

Why is this study being done?
There is very limited research with children with disabilities in India that provides avenues for listening to first-hand experiences of children with disabilities, as well as research that involves them as collaborators. The ability to participate in meaningful occupations can support child development, promote health and well-being and address their inclusion in society. This project seeks to involve children with disabilities as collaborators in choosing a specific topic related to their occupational participation that they would like to explore in order to work towards addressing the need for children with disabilities to participate in occupations within their community.

How long will you be in this study?
If you choose to take part in this study, you will be asked to take part in one group meeting (2 hours long) with other community members over the course of the project that is for 6-8 months. You can leave the meeting when you want and be as involved as much as you would like.

What are the study procedures?
If you agree to participate in this project, you will be asked to participate in one group meeting with other community members. The meeting will be two hours long and will be conducted in an accessible and convenient location. The meeting will focus on hearing community members’ perspectives about the disseminated video created by children with disabilities and their experiences.
The meeting will be audio-recorded and transcribed into English to explore ideas that emerge from this meeting regarding the experiences of children with disabilities within your community.

**What are the risks and harms of participating in this study?**
Within the context of a group discussion, people may say things that they do not want to be transmitted to others outside of the group, which can lead to a risk of privacy breach and issues related to confidentiality. Thus, at the beginning of each group meeting, the facilitators will have a discussion regarding confidentiality and privacy, and ask people not to discuss what is discussed in the group with people outside the group once the group is finished. Participants can control what they reveal/do not reveal about themselves within the context of group discussions.

**What are the benefits of participating in this study?**
There are no direct benefits associated with your participation in this research project. The information you share might help address issues related to the occupational participation of children with disabilities within your community. The information you share will be presented to others through publications and at conferences and meetings. Your identity will not be released in any publications or presentation. If you want, a copy of the study results can be forwarded to you at the completion of the study.

**Can participants choose to leave the study?**
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future. Information collected prior to withdrawal will be kept, unless you ask to have it removed from the study. You have the right to request withdrawal of information collected about you. If you wish to have your information removed, please let the researcher know. It may be challenging within a group discussion to remove one person’s contribution, but we will attempt to remove it. You do not have to be in this study if you do not wish to be. You do not have to answer questions in the meeting. You do not have to talk about anything in the meeting that you do not want to.

**How will participants’ information be kept confidential?**
Representatives of the University of Western Ontario Health Sciences Research Ethics Board may require access to your study-related records for monitoring purposes.

The group meeting will be audio-recorded. What you say will be typed out by a typist and translated in English, and all identifying information will be removed from these notes. The only people who will listen to the recordings will be members of the research team and the typist and translator. The only people who will read the meeting transcript will be the research team.

To protect your identity and maintain confidentiality of information, only an identification number will be used instead of your name to identify recordings, notes, and transcripts. You are free to request that parts of the recording be erased, either during or after the group meeting. The consent form, notes and recordings will be locked in a secure place at Christian Medical College, and all information transferred into typed format and digital files will be
de-identified and stored in a password protected and encrypted laptop. All information will be erased after 7 years.

While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report.

Quotes that you share during the meeting will be included in future publications and presentations and will be identified using fictional names. Personal details will be changed to ensure your anonymity.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of group meeting discussions prevents the researchers from guaranteeing complete confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the group meeting to others.

**Are participants compensated to be in this study?**
You will not be compensated to participate in this study. We will provide snacks and refreshments at the meeting.

**What are the rights of participants?**
Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study, it will have no effect on your employment or services received. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

**Whom do participants contact for questions?**
You will be given a copy of this letter of information and consent form once it has been signed. If you have any questions or want any additional information, you may contact Tanya Benjamin at [tbenjam4@uwo.ca](mailto:tbenjam4@uwo.ca) or by telephone at [7825053255](tel:7825053255).

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics on [1](tel:1) 519-3036, email: [ethics@uwo.ca](mailto:ethics@uwo.ca) or Christian Medical College, office of Research at [0](tel:0) 416-2284294, email: [research@cmcvellore.ac.in](mailto:research@cmcvellore.ac.in).

This letter is yours to keep for future reference.
Christian Medical College, Vellore  
Department of Community Health

Consent- Community Members Viewing the Created Videos

Study Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator 
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,  
Western University, London, Ontario  
Email: hidden

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor  
Professor, School of Occupational Therapy  
Western University, London, Ontario  
Email: hidden

Dr. Vinod Joseph Abraham, Doctoral advisory committee member  
Professor, Department of Community Health,  
Christian Medical College, Bagayam,  
Email: hidden; Phone: +91 9443253772

[ ] I confirm that I have read the Letter of Information and have had all questions answered to  
my satisfaction

[ ] I agree to participate in this research

[ ] I agree to be audio-recorded in this research

[ ] I agree for my contact information to be kept by the researcher for the purposes of sharing  
with me the final results of this project after completion

[ ] I consent to the use of de-identified quotes obtained during the study in the dissemination  
of this research

__________________________  
Print Name of Participant

__________________________  
Signature

__________________________  
Date (DD-MM-YYYY)

My signature means that I have explained the study to the participant named above. I have  
answered all questions.
<table>
<thead>
<tr>
<th>Name of Person Obtaining Consent</th>
<th>Signature</th>
<th>Date (DD-MM-YYYY)</th>
</tr>
</thead>
</table>

[ ] The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

<table>
<thead>
<tr>
<th>Name of Witness</th>
<th>Signature</th>
<th>Date (DD-MM-YYYY)</th>
</tr>
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</table>

Relationship to Participant
Appendix P: Tamil Letter of Information and Consent - Community Members Viewing the Video

Subject: Tamil Letter of Information and Consent - Community Members Viewing the created videos

Dear Community Members:

This letter serves as a formal consent form for your participation in the video creation project. As a member of our community, we are reaching out to you to seek your voluntary participation in the creation of educational videos.

By signing this letter, you are agreeing to the following:

1. You consent to being recorded and to your voice and/or image being used in the creation of the videos.
2. You consent to the use of your name and/or likeness in promotion and dissemination of the videos.
3. You understand that your participation is voluntary and that you may withdraw your consent at any time without any consequences.
4. You agree to the use of any personal information that you may provide as required for the purposes of the video project.

We value your trust and confidentiality. All information collected will be used solely for the purpose of the video project and will not be shared with any third parties.

By signing below, you acknowledge and agree to the terms stated above:

[Signature]

Date: [Date]

[Name]

Contact Information:

[Phone Number]

[Email Address]

If you have any questions or concerns, please do not hesitate to contact us.

Sincerely,

[Name]

[Title]

[Institution]
செயல்பாடு நூற்றாண்டு அரசியல் நூற்றாண்டு அரசியல் நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்டு நூற்றாண்...
பொதுச்சொல் 55:

வேலூர் மக்கள் தெருவின் நூற்றாண்டு அறிமுகம்

காலம் தொடர்பான வேறுபட்டு பொருள்கள்

பொருளாயிறு முயற்சிக்கும் பொருள் வளர்ச்சியானது

அரசு குழுவின் கீழ் வருந்தம் பட்டியல்கள்

செயல்பாடு செயல்பாடு வேதியியல் வீச்சக கோபுரத்தில்

பொருளாயிறு முயற்சிக்கும் பொருள் வளர்ச்சியானது

காலம் தொடர்பான வேறுபட்டு பொருள்கள்

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352
சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. தமிழ்நாட்டின் சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. 

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சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. 

சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. 

சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. 

சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. 

சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது. சிறா என்றுள்ளது பொருளின் வலுவான எளிதாக வைக்கப்பட்டுள்ளது.
The office of Human Research Ethics

+1 (519) 661-3036, Email: ethics@uwo.ca

The office of Research at 0416-2284294, Email: research@cmcvellore.ac.in
Appendix Q: English Letter of Information and Consent - Photographed Subjects

Letter of Information for Person Having His/Her Picture Taken

Project Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont.), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,
Western University, London, Ontario

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario

Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health,
Christian Medical College, Bagayam,

Invitation to Participate
You are being asked by a research participant in a research project to have a photo taken of you or to be part of a video. This project aims to explore if and how children with disabilities participate in occupations within the context of their daily lives, with an intent to promote avenues to increase their occupational participation. In this project, occupation is defined as the everyday activities that people do as individuals and collectives.

This study is using a digital methodology called ______________ as part of a participatory action research (PAR) study in which children with disabilities will be collaborators in: a) exploring if and how they participate in everyday occupations within the context of their daily lives; b) identifying supports and barriers related to their occupational participation; c) envisioning what they need and want in terms of participating in occupations at home and in the society; and, d) working with community stakeholders towards addressing identified barriers and utilizing supports to promote their occupational participation. To address these objectives, the participating children will be using cameras to take videos and pictures of persons, objects and places as a way to communicate their occupational experiences within group meetings with other children with disabilities. Some of these pictures might be taken at the photographer’s home, school and/or the community setting, and may include other people in the setting. The photographer has been trained on taking pictures and videos in a manner that does not reveal your identity.
The purpose of this letter is to provide you with necessary information so you can make an informed decision about your participation within this research project. Prior to having your picture or video taken, you have been provided with the letter of information about this study and you must sign a Consent Form giving permission for your picture or video to be taken. Your photographer will have the Consent Form for you to sign. If you are a child (18 years of age or younger), your parent/guardian must be present to consent on your behalf, and you must provide an assent to participating.

Your photographer, will be involved in a series of group meetings with other children with disabilities and researchers, and will share about what this video/photo means to him/her. The video clips or photos will be used to create a video with other video clips and pictures.

What are the risks and harms of participating in this study?
There may be some risks related to your identification within visuals (photos or videos). Participants have been trained on how to take photos and videos without the use of identifiable information within the visuals and it will be established within the training that only non-identifiable visuals will be used within the context of this research project. In addition, if any photos or videos have any sort of identifiable information, the identifiable information will be removed through editing the image or video (e.g., faces blurred).

What are the benefits of participating in this study?
By allowing your picture or video taken, you are assisting others to better understand if and how children with disabilities participate in occupations within your community, which will help address issues related the occupational participation of children with disabilities.

What happens to the pictures or videos?
To protect your identity, your personal information (e.g., name) will not be associated with pictures and videos and only numbers or pseudonyms will be used. Your picture or video, after identifiable information has been removed, it may be used by children along with other photos and videos to create narratives or a video. If you provide consent, and if the children are interested, the final created narratives or video will be disseminated on various platforms to facilitate a better understanding on the occupational participation of children with disabilities. You can choose how you want any photos or videos that include you to be used in the study, including who they will be shared with and how they will be shared. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your permission.

Other information about this study:
You do not have to permit your picture or video to be taken if you do not wish to. If you have any additional questions or require additional information, please contact Tanya Benjamin.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics +1 (519) 661-3036, email: ethics@uwo.ca or Christian Medical College, office of Research at 0416-2284294, email: research@cmcvellore.ac.in

This letter is yours to keep for future reference.

Version Date: 19/03/2018
Consent to Photograph-Person Having His/Her Picture Taken

**Study Title:** Promoting the Occupational Participation of Children with Disabilities

I, _________________________________________________________ (please print name of person being photographed), hereby authorize _______________________________________ (name of photographer) to take a photographic image or video of me for a research project. It is understood that I may request the opportunity to view the photograph(s) or video(s), and that I have the right to request that the image(s) and video(s) be destroyed.

Please check if you are okay with your photograph(s) or video(s) being:

- [ ] Shared with researchers
- [ ] Shared with other study participants
- [ ] Shared in a gallery or display
- [ ] Shared in a research presentation or at a conference
- [ ] Shared in a published article or paper
- [ ] Shared in a website on the internet

Please check if you want the photo(s) or video(s) to be modified (e.g. faces blurred or covered) prior to being shared with persons outside of the research project. __________

Please note that once your photo is published in a public domain, you will not be able to remove or delete it.

_________________________________
Signature of the Photographed

_________________________________
Signature of Participant

_________________________________
Date

[ ] My signature means that I have explained the study to the participant named above. I have answered all questions.

_________________________________
Name of Person Obtaining Consent

_________________________________
Signature

______________       ______________       __________________
Name of Person Obtaining Consent                    Signature                    Date (DD-MM-YYYY)
The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

____________________________       ___________________       __________________
Name of Witness       Signature       Date (DD-MM-YYYY)

Relationship to Participant
Appendix R: Tamil Letter of Information and Consent - Photographed Subjects

Letter of Information for person Having His/Her picture taken

The Tamil Letter of Information and Consent is presented here in English for clarity.

Appendix R: Tamil Letter of Information and Consent - Photographed Subjects

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The Tamil Letter of Information and Consent is presented here in English for clarity.
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தியா புலியான்களின் எதிர்முனையில் போன்றுவரும் உருசியப் பேச்சுகள் தடையாய் பயன்படுத்தப்பட்டு. நோய்கள், பிசுலியா நல்லையே பயன்படுத்தப்பட்டு, மூலம் பிரித்தந்த புகழ் மறைந்துவிட்டு, குற்றுபாட்டுச் சொல்கள் நோய்களுக்கு இன்று இருப்பிட்டன. போரின் விளக்கத்தை கொண்டே நோய்கள் பயன்படுத்தத் தொடங்கினார்கள்.

நோய்களும் போர்களும், போர்களுடன் விளக்கத்தை கொண்டு பயன்படுத்தத் தொடங்கினார்கள். போரின் விளக்கத்தை கொண்டே நோய்கள் பயன்படுத்தத் தொடங்கினார்கள். மூலம் பிரித்தந்த புகழ் மறைந்துவிட்டு, குற்றுபாட்டுச் சொல்கள் நோய்களுக்கு இன்று இருப்பிட்டன. போரின் விளக்கத்தை கொண்டே நோய்கள் பயன்படுத்தத் தொடங்கினார்கள்.

சிறந்த குறிப்பிட்டத் தொடங்கினார் சிறந்த குறிப்பிட்டத் தொடங்கினார் குறிப்பிட்டத் தொடங்கினார் குறிப்பிட்டத் தொடங்கினார் குறிப்பிட்டத்தை கொண்டே நோய்கள் பயன்படுத்தத் தொடங்கினார்கள். போரின் விளக்கம் பொருகினாள், நோய்கள் பொருத்துவது குறிப்பிட்டத்தை கொண்டே நோய்கள் பயன்படுத்தத் தொடங்கினார்கள். (சிறந்த குறிப்பிட்டத் தொடங்கினார் 18 வருட குறிப்பிட்டத் தொடங்கினார் நோய்கள் பொருகினாள்) போரின் விளக்க தொடங்கினாள் நோய்கள் பயன்படுத்தத் தொடங்கினாள். குறிப்பிட்டத் தொடங்கினாள் நோய்கள் பயன்படுத்தத் தொடங்கினாள்.

சிறந்த குறிப்பிட்டத் தொடங்கினாள் நோய்கள் பயன்படுத்தத் தொடங்கினாள் குறிப்பிட்டத் தொடங்கினாள் குறிப்பிட்டத் தொடங்கினாள் குறிப்பிட்டத் தொடங்கினாள் குறிப்பிட்டத்தை கொண்டே நோய்கள் பயன்படுத்தத் தொடங்கினாள். போரின் விளக்கம் பொருகினாள், நோய்கள் பொருத்துவது குறிப்பிட்டத்தை கொண்டே நோய்கள் பயன்படுத்தத் தொடங்கினாள். (சிறந்த குறிப்பிட்டத் தொடங்கினாள் 18 வருட குறிப்பிட்டத் தொடங்கினாள் நோய்கள் பொருகினாள்) போரின் விளக்க தொடங்கினாள் நோய்கள் பயன்படுத்தத் தொடங்கினாள். குறிப்பிட்டத் தொடங்கினாள் நோய்கள் பயன்படுத்தத் தொடங்கினாள்.
The office of human research ethics +1(519) 661-3036, email: ethics@uwo.ca

office of Research at 0416-2284294, email: research@cmcvellore.ac.in

The office of human research ethics

office of Research at

The office of human research ethics

office of Research at
Consent to photograph – person having His/ Her picture taken

Name ____________________________ (Name of the person having His/ Her picture taken)

__________________________________ (Name of the person who is taking the picture)

Date of Birth: ___________________ (Date of Birth)

Consent to photograph – person having His/ Her picture taken

Purpose of the photograph:

__________________________________

Signature: ____________________________

Date: _______________________________

__________________________________

Revised: ________________________________

Printed Name: __________________________

Signature: ____________________________

Date: _______________________________

__________________________________

By: ____________________________

Date: ________________________________

Note: The consent form is to be signed by the person having the picture taken and the person taking the picture. The purpose of the photograph should be clearly mentioned. The signature and date of the consent should be clearly visible.

Printed Name: __________________________

Signature: ____________________________

Date: ________________________________

Note: The consent form is to be signed by the person having the picture taken and the person taking the picture. The purpose of the photograph should be clearly mentioned. The signature and date of the consent should be clearly visible.

Printed Name: __________________________

Signature: ____________________________

Date: ________________________________

Note: The consent form is to be signed by the person having the picture taken and the person taking the picture. The purpose of the photograph should be clearly mentioned. The signature and date of the consent should be clearly visible.

Printed Name: __________________________

Signature: ____________________________

Date: ________________________________

Note: The consent form is to be signed by the person having the picture taken and the person taking the picture. The purpose of the photograph should be clearly mentioned. The signature and date of the consent should be clearly visible.

Printed Name: __________________________

Signature: ____________________________

Date: ________________________________

Note: The consent form is to be signed by the person having the picture taken and the person taking the picture. The purpose of the photograph should be clearly mentioned. The signature and date of the consent should be clearly visible.
Appendix S: Assent for Photographed Subjects in English

Study Title: Promoting the Occupational Participation of Children with Disabilities

Researchers
Tanya Elizabeth Benjamin, PhD Candidate, OT Reg (Ont), Doctoral Student Investigator
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science,
Western University, London, Ontario
Email: tbenjam4@uwo.ca

Dr. Debbie Laliberte Rudman, PhD, OT Reg. (Ont), Doctoral supervisor
Professor, School of Occupational Therapy
Western University, London, Ontario
Email: drudman@uwo.ca

Dr. Vinod Joseph Abraham, Doctoral advisory committee member
Professor, Department of Community Health,
Christian Medical College, Bagayam,
Vellore 632002, Tamil Nadu, India
Email: vinodabraham@cmcvellore.ac.in
Phone: +91 9443253772

Why are you being Asked to be in a Picture or Video?
The photographer has been asked to take videos or pictures relevant to them about the occupational experiences of children with disabilities within their community. These photo(s) and video(s) will be used in a research project to explore if and how children with disabilities participate in occupation and to increase opportunities for children with disabilities to participate in occupations meaningful to them. Tanya Benjamin and some other researchers are doing this project.

What will Happen to You?
You will have photo(s) or video(s) of you taken. Your photographer will share your video or picture with other children with disabilities to facilitate shared discussion about the occupational participation of children with disabilities within your community. The photos or videos taken of you will not include any identifiable information (e.g., your face) and if any identifiable information is present, it will be removed or edited so that it is not revealed (e.g., blurring or covering of faces).

What will Happen to the Picture or Video?
The photo(s) or video(s) taken of you will be shared with other children in a group meeting and may be used with other videos and photos to create narratives or a video. If you provide consent, and if the children are interested, the final created narratives or video will be disseminated on various platforms to facilitate a better understanding on the occupational participation of children with disabilities. You can choose how you want any photos or videos that include you to be used in the study, including who they will be shared with and how they will be shared. The researchers might use pictures from the videos in academic articles (magazines for adults and researchers), academic books (text books for adults and older students in college) and the videos or stills in academic presentations (presentations for teachers, therapists and researchers) if that is okay with you.

**Will This Study Help You?**
No, this study will not directly help you but in the future it might help address issues related to occupational participation that children with disabilities face within your community.

**What if you have any questions?**
You can ask questions any time, now or later. You can talk to Tanya, your parents, or any of the researchers.

**Do you have to be in the study?**
No, you do not have to participate in this study if you do not want to. No one will be mad at you if you do not want to be involved. Even if you say yes, you can change your mind later and withdraw from the study at any time.

[ ] I confirm that the Letter of Information has been read to you and have had all questions answered to your satisfaction

I agree that any photo(s) or videos of me may be:
- Shared with researchers [ ]
- Shared with other study participants [ ]
- Shared in a gallery or display [ ]
- Shared in a research presentation or at a conference [ ]
- Shared in a published article or paper [ ]
- Shared in a website on the internet [ ]

Please note that once your photo or video is published in a public domain, you will not be able to remove or delete it.

Print Name of Participant  Signature  Date (DD-MM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Name of Person Obtaining Consent  Signature  Date (DD-MM-YYYY)
[ ] The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

<table>
<thead>
<tr>
<th>Name of Witness</th>
<th>Signature</th>
<th>Date (DD-MM-YYYY)</th>
</tr>
</thead>
</table>

Relationship to Participant
Appendix T: Assent for Photographed Subjects in Tamil

Assent for Child Having His / Her Picture Taken

©2018 July 19

R.A. Ráj A. Vinodabraham, M.D., Ph.D.

Appendix T: Assent for Photographed Subjects in Tamil

Assent for Child Having His / Her Picture Taken

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Appendix T: Assent for Photographed Subjects in Tamil

Assent for Child Having His / Her Picture Taken
தினகையாகும் முக்கியமான / முழுமையான புரோட்டங்கள் நேராக இணைக்கப்படும் முறையில் நோக்கக் கையெடுப்பும். மூலம் அது புரோட்டங்கள் / சிறுகுழந்தைகளுக்கு வாழ்க்கையாக பயன்படுத்தும். வேளாண்மைத் தீர்வுகளை மேம்படுத்தும். என்று தீர்வுகளை அளிக்கும் வருடாக முழுமையான புரோட்டங்கள் நேராக இணைக்கப்படும் முறையில் நோக்கக் கையெடுப்பும்.

மிகு ஒப்புதலும் முக்கியத்துவம் என்றோம்?

முன்னுரையில் முக்கியத்துவம் எனவும் அளிக்கப் படுகின்றதும், முக்கியமான தீர்வுகள் முன்னேறும் முறையில் இணைக்கப்படும். வாழ்க்கையாக பயன்படுத்தும் வேளாண்மைத் தீர்வுகளை மேம்படுத்தும்.

முக்கியத்துவம் வழங்கும் தீர்வுகள் என்றோம்?

முன்னுரையில் முக்கியத்துவம் எனவும் அளிக்கப் படுகின்றதும், வாழ்க்கையாக பயன்படுத்தும் வேளாண்மைத் தீர்வுகளை மேம்படுத்தும். முக்கியமான தீர்வுகள் இணைக்கப்படும்.

[ ] முன்னுரையில் முக்கியத்துவம் எனவும் அளிக்கப் படுகின்றதும், வாழ்க்கையாக பயன்படுத்தும் வேளாண்மைத் தீர்வுகளை மேம்படுத்தும்.

முக்கியமான / முழுமையான புரோட்டங்கள் நேராக இணைக்கப்படும்.

- கூற்றும் துவாரக்காரனின்
- கூற்றும் துவாரம் பொருளாக்கற்றும்
- கூற்றும் துவாரம் பொருளாக்கற்றும்
- கூற்றும் துவாரம் பொருளாக்கற்றும்
- கூற்றும் துவாரம் பொருளாக்கற்றும்
- கூற்றும் துவாரம் பொருளாக்கற்றும்
- கூற்றும் துவாரம் பொருளாக்கற்றும்
- கூற்றும் துவாரம் பொருளாக்கற்றும்

முன்னுரையில் முக்கியத்துவம் எனவும் அளிக்கப் படுகின்றதும், வாழ்க்கையாக பயன்படுத்தும் வேளாண்மைத் தீர்வுகளை மேம்படுத்தும் முறையில் நோக்கக் கையெடுப்பும்.

முன்னுரையில் முக்கியத்துவம் எனவும் அளிக்கப் படுகின்றதும், வாழ்க்கையாக பயன்படுத்தும் வேளாண்மைத் தீர்வுகளை மேம்படுத்தும் முறையில் நோக்கக் கையெடுப்பும்.

புத்தாண்டு புகழ்: 19.03.2018
புகழ் பெறும் பொருளாதாரத்திற்கான காந்திக் காற்றுடன், நியுட்பு பெயருடைய இருபது குறல் தொகுப்பு நிற்கும் உரையாட்டம் செய்யப்பட்டது. இது நிற்பு பெயர் இயற்கை வர்த்தகரின் நோக்கங்கள் வாய்ந்த செயல்பாடுகளை குறிப்பிட்டுள்ளது.

புரீட்டமைப்பதற்கு எடுத்துக்காட்டு.

நூறு பெயருறவியின் தொடர் மற்றும் பெயர் (பொருள்/செயல்பாடு/புரீட்டுணிக்கை)
Appendix U: Demographic Questionnaire English and Tamil Versions

Demographic Questionnaire – Parents / Guardians of Children with Disabilities

Name of Parent/Guardian:

Relationship to the child:

Parent/Guardian Age:

Name of the village the child is residing in:

Telephone number:

Address:

Socio-Economic status of the Family:

Annual Household Income:

Date: 19.03.2018
Each Month the family has:

- More than enough money for necessary resources
- Just enough money for necessary resources
- Does not have enough money for necessary resources

Child’s Name:

Child Age:

Child Gender:

Type of Disability:

Is the child presently attending school? [ ] Yes [ ] No

If no, what is the reason for not attending school?
Appendix V: Focus Group Guides in English

Christian Medical College, Vellore
Department of Community Health

Focus Group Guides

Parents/Guardians of Children with Disabilities

These guiding questions will support parents/guardians in sharing about their thoughts regarding their child’s participation within this project

1. Why did you decide for your child to participate within this research project?
2. Do you feel like your child has learned something new from participating within this research process? Please explain?
3. What have you learnt from your child participating within this research project?
4. Do you think about your child differently as a result of seeing his/her participation within this project?
5. Do you think that their participation within this project will help bring about change? If yes, what kinds of change?
6. Have there been any changes in your child that you have noticed after he/she has been involved within this project?
Community Focus Group Guide: Situating Disability within the Research Context

These guiding questions will be used to guide focus group discussions with parents, teachers and other service providers about how disability is situated within that specific context.

1. From your perspective, what are the everyday experiences of children with disabilities within your community?

2. What types of occupations do children with disabilities engage in within that specific context?
   a. What are some barriers to occupational participation that children with disabilities experience?
   b. What are some supports to the occupational participation of children with disabilities?

3. What kinds of change would you envision with regard to children with disabilities and their occupational participation?
Focus Group: Guiding Questions for Research Volunteers

These guiding questions will be used to guide focus group discussions with research volunteers, for them to discuss and share their experiences of participating within this research process.

1. Why did you decide to participate in this research process?
2. What did you enjoy most about this process?
3. If we have to repeat this project, what would you keep the same and what would you change?
4. What did you learn about yourself through this project?
5. What did you learn about the occupational participation of children with disabilities?
6. Do you think this project will bring about change? If yes, what type of change do you envision?
Focus Group: Guiding Questions for Children (Participatory Research Phase)

Discussions related to creating their Video (SHOWeD: Wang, Cash, Powers, 2000; ORID: Stanfield, 2000): When children choose specific photos or video clips to use within their video projects, these guiding questions will help to guide discussions about the media they create/select.

1. What do you See here?
2. What is happening here?
3. How does this relate to our lives?
4. Why does this problem, concern or strength exist?
5. What can we do about it?
6. What do you know when seeing or listening to this?
7. What do you feel?
8. What does this mean?
9. What do we do?
10. Why did you specifically choose this media component (e.g., video/image/music)?

Discussions Related to the Participatory Action Research Process

1. Why did you decide to participate in this research process?
2. What did you enjoy most about this process?
3. If we have to repeat this project, what would you keep the same and what would you change?
4. What did you learn about yourself through this project?
5. What did you learn about the occupational participation of children with disabilities?
6. Do you think this project will bring about change? If yes, what type of change do you envision?
7. Where would you like to share the created video (s)? and Why?
Community Focus Group Guide

These guiding questions will be used to guide focus group discussions with community members who watch the video created by children and youth.

1. What are your thoughts about this video?
2. What did you learn from the video? Anything that stood out to you in particular? And Why?
3. Do you agree or disagree with what you saw within the video and why?
4. What are your thoughts about the occupational experiences of children with disabilities within your community?
5. What are some barriers and supports to the occupational participation of children with disabilities within your community?
6. How do you think we can promote the occupational participation of children with disabilities within this communities?
7. What do you envision for children with disabilities in terms of their occupational participation within this community?
8. Would you like to be involved in addressing this issue related to the occupational participation of children with disabilities within your community? If yes, in what way?
Appendix W: Focus Group Guides in Tamil

Focus Group Guides

1. இருவர் அமையும் கைக்கூட்டில் ஈடுபாட்டில் பகுதிக்கூட்டில் பாங்கங்கள் மற்றும் ஸ்டீடிக்கர்கள்?

2. இருவர் அபிலிக்காக கைக்கூட்டில் பாங்கங்கள் மற்றும் ஸ்டீடிக்கர்கள் பாதுச்சாதனை?

3. கைக்கூட்டில் பாங்கங்கள் மற்றும் ஸ்டீடிக்கர்கள் பாதுச்சாதனை?

4. இருவர் அமையும் கைக்கூட்டில் எசுக்கொட்டிய பாது / அவை பாது இணையமாக வெளியீடு பிரிப்பாக்கம்?

5. இருவர் அமையும் கைக்கூட்டில் எசுக்கொட்டிய பாது / அவை பாது இணையமாக வெளியீடு பிரிப்பாக்கம்?

6. இருவர் அமையும் கைக்கூட்டில் எசுக்கொட்டிய பாது / அவை பாது இணையமாக வெளியீடு பிரிப்பாக்கம்?
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ஒலிப்பாடு அசலக்கையானது உண்மையானது: கூறுகள் குறிப்பிட்டிட்டு செய்ய முடிகிறது

முன்னேற்றங்கள், இருக்கிறது பல வகையான ஒலிப்பாடுகள் உண்மையானது செய்ய முடிகிறது சுயத்ரவிசையான நூற்றாண்டுகள் கூற்றுகள் குறிப்பிட்டிட்டு செய்ய முடிகிறது அல்லது தமிழ்நாட்டிலுள்ள எதிர்காலத்தில் சுயத்ரவிசையான நூற்றாண்டுகள் கூற்றுகள் குறிப்பிட்டிட்டு செய்ய முடிகிறது அல்லது தமிழ்நாட்டிலுள்ள எதிர்காலத்தில் சுயத்ரவிசையான நூற்றாண்டுகள் கூற்றுகள் குறிப்பிட்டிட்டு செய்ய முடிகிறது.

1) எதிர்காலத்திலுள்ள எளிய கூறுகளை தமிழ்நாட்டிலுள்ள எளிய கூறுகளை செய்ய முடிகிறது என்ன என்ன என்ன என்ன?

2) இருக்கிறது தமிழ்நாட்டிலுள்ள கூறுகளை தமிழ்நாட்டிலுள்ள எளிய கூறுகளை செய்ய முடிகிறது என்ன என்ன என்ன என்ன?
   a) இருக்கிறது தமிழ்நாட்டிலுள்ள எளிய கூறுகளை தமிழ்நாட்டிலுள்ள எளிய கூறுகளை செய்ய முடிகிறது என்ன என்ன என்ன என்ன?
   b) இருக்கிறது தமிழ்நாட்டிலுள்ள எளிய கூறுகளை தமிழ்நாட்டிலுள்ள எளிய கூறுகளை செய்ய முடிகிறது என்ன என்ன என்ன என்ன?

3) எதிர்காலத்திலுள்ள எளிய கூறுகளை தமிழ்நாட்டிலுள்ள எளிய கூறுகளை செய்ய முடிகிறது என்ன என்ன என்ன என்ன என்ன?
1. தீன்று எகமன்றிக் கீழ்க்குறிக்கை தொடர் பரிமாற்றத்தை வருகையைப் பெற்று வழக்கத்தைப் படையும் பொழுது வேளாண்மையில் என்று வேளாண்மையில் என்று வேளாண்மையில் என்று வேளாண்மையில்

2. தீன்று எகமன்றிக் கீழ்க்குறிக்கை தொடர் பரிமாற்றத்தை வருகையைப் பெற்று வழக்கத்தைப் படையும் பொழுது வேளாண்மையில் என்று வேளாண்மையில் என்று வேளாண்மையில்

3. பெற்றோம் சிற்றிக் கீழ்க்குறிக்கை தொடர் பரிமாற்றத்தை வருகையைப் பெற்று வழக்கத்தை

4. சிற்றிக் கீழ்க்குறிக்கை தொடர் பரிமாற்றத்தை

5. மொழியறிதல் எகமன்றிக் கீழ்க்குறிக்கை தொடர் பரிமாற்றத்தை

6. சிற்றிக் கீழ்க்குறிக்கை தொடர் பரிமாற்றத்தை

பிறப்பு துன்றம் 19.03.2018
1. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
2. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
3. பிறக்கும் மண்டலக் கூட்டாட்சிகளின் சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
4. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
5. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
6. பிறக்கும் மண்டலக் கூட்டாட்சிகளின் சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
7. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
8. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
9. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
10. பிறக்கும் மண்டலக் கூட்டாட்சிகளின் சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;

1. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
2. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
3. பிறக்கும் மண்டலக் கூட்டாட்சிகளின் சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
4. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
5. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
6. பிறக்கும் மண்டலக் கூட்டாட்சிகளின் சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
7. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
8. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
9. சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
10. பிறக்கும் மண்டலக் கூட்டாட்சிகளின் சிறை வரும் பின்னர் மாதிக்கப்பட்டுள்ளது;
சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று குறிப்பிட்டு சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள்

1) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன? 2) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன? 3) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன? 4) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன? 5) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன? 6) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன? 7) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன? 8) சுருக்கலப் புத்தகம் உரோட்டுற்று முகமது ராஹிம் கல்வித்துற்று முடிக்கும் பகுதிகள் என்ன?
Appendix X: Certificate of Translation

CERTIFICATE OF TRANSLATION

I, S. Chandrasekaran, certify that the translation of documents, from English to Tamil, submitted to the ethics board at Western University, London, Canada and Christian Medical College Vellore, India, for the research project titled: *Working Towards Promoting the Occupational Participation of Children with Disabilities through Participatory Action Research*, is a true and accurate representation of the original document.

Signed on February 20, 2018 in Madurai, Tamil Nadu, India.

S. Chandrasekaran

Ph: +91 9843415325
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RE: Request for Permission to Use Copyrighted Material in a Doctoral Thesis

Clare Hocking

Sun 4/28/2019 7:01 PM

To: Tanya Elizabeth Benjamin

Hello Tanya
Thank you for contacting me.
Yes, I confirm that these arrangements meet my approval
Clare

From: Tanya Elizabeth Benjamin
Sent: Sunday, 28 April 2019 2:30 PM
To: Clare Hocking
Subject: Request for Permission to Use Copyrighted Material in a Doctoral Thesis

April 27, 2019

Dear Prof. Hocking,

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Tanya Elizabeth Benjamin

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Tanya Benjamin
Tanya Elizabeth Benjamin, MS, OT, OT Reg. (Ont.), PhD Candidate,
Graduate Program in Health and Rehabilitation Sciences, Field of Occupational Science
Faculty of Health Sciences
Western University, London, Ontario.
Curriculum Vitae

Tanya Elizabeth Benjamin

EDUCATION

Doctor of Philosophy in Health and Rehabilitation Sciences 2015 – present
Field of Occupational Science, Faculty of Health Sciences, Western University, London, Ontario, Canada
Thesis Title: Enacting Occupation-based Transformative Research through Participatory Filmmaking with Children with Disabilities
Supervisor: Dr. Debbie Laliberte Rudman

Master of Science in Occupational Therapy 2013 – 2014
Colorado State University, Fort Collins, Colorado, USA
Thesis Title: Participation in Early Childhood Educational Environments for Young Children with and without Developmental Delays: A Mixed Methods Study
Supervisor: Dr. Mary Khetani

Bachelor of Occupational Therapy Professional Degree 2006 – 2010
Christian Medical College, Vellore, Tamil Nadu, India
Affiliated with Dr. M.G.R Medical University, Chennai, Tamil Nadu, India
Thesis Title: Validation of the Sensory Profile Tool among children with autism in the Indian population
Supervisor: Mr. Sanjeeve M Padankatti

FELLOWSHIPS & EXCHANGE PROGRAMS

Fellow, Global Mental Health Incubator for Disruptive Solutions (Global MINDS) at Western University, Canada, in collaboration with the Africa Mental Health Foundation, Kenya 2017 – 2018
International Presidential Fellow, Colorado State University, USA 2013 – 2014
Linnaeus Palme Scholar & Exchange Student, Orebro University, Sweden 2011

AWARDS, GRANTS, & SCHOLARSHIPS

Ontario Trillium Scholarship, $40,000 CAD/year, for up to 4 years 2015 – 2019
Western Graduate Research Scholarship, $33,000 CAD 2015 – 2018
Christian Medical College, Vellore, Fluid Research Grant, 18, 846 INR 2018
Health & Rehabilitation Sciences Conference Travel Award, $700 CAD 2017 – 2018
Faculty of Health Sciences Conference Travel Award, $500 CAD 2017 – 2018
Health & Rehabilitation Sciences Conference Travel Award, $400 CAD 2016 – 2017
Faculty of Health Sciences Conference Travel Award $260 CAD 2016 – 2017
Graduate Excellence Award, Graduate Research Showcase, Colorado State University $200 USD 2015
Karnataka Minority Overseas Scholarship, Government of Karnataka, India, 500,000 INR 2014 – 2015
Occupational Therapy Travel Award, Colorado State University, $1000 USD 2014
Elnora Gilfoyle Scholarship, Colorado State University, $1790 USD 2014 – 2015
International Merit Work-Study Award, Colorado State University $6000 USD 2013 – 2014
Linnaeus-Palme Scholarship, Government of Sweden, 40,000 SEK 2011
Dr. Mary Varghese Medal, Best Outgoing Student, Christian Medical College, India 2010
Ms. Jean Bald Medal, Best All Rounder, Christian Medical College, India 2010
First rank proficiency, 4th year Occupational Therapy, Christian Medical College, India 2010
First rank proficiency, 3rd year Occupational Therapy, Christian Medical College, India 2009
First rank proficiency, 2nd year Occupational Therapy, Christian Medical College, India 2008

**SUMMARY OF RESEARCH CONTRIBUTIONS**

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**REFEREED PUBLICATIONS**


**REFEREED PRESENTATIONS**


*Canadian Coalition for Global Health Research Student Mentee


NON-REFEREED PRESENTATIONS

Ontario, Canada.

**Equal contribution


**Equal contribution


**Equal contribution


**INVITED TALKS


**MEDIA PUBLICATION

TEACHING EXPERIENCE

Teaching Assistant
Course: Health Policy 3400A, Western University, London, Canada,
Fall, 2017

Invited Guest Lectures

*Western University, London, Canada*
Course: HS 9660/9760, Occupational Science: Foundations, Perspectives and Research, Winter 2019
Lecture titled: Enacting Transformative Occupation-Based Research: Making Transparent a Participatory Filmmaking Project with Children with Disabilities.
Course Coordinator: Dr. Debbie Laliberte Rudman

Invited Guest Lectures

*Western University, London, Ontario, Canada*
Course: 3400A Health Policy, Fall 2017
Lecture titled: Participatory Action Research with Children with Disabilities.
Course Coordinator: Melanie McPhail

*Baptist Christian Hospital, Assam, India*
Event: School teacher conference
Lecture titled: School-based Interventions for Children with Disabilities
May, 2013

Academic Mentorship Roles

*Global MINDS Fellowship Program*
Catalyst coach for a student-faculty-community partner triad team 2019-2020

*Coalition of Global Health Research Western University Chapter*
Research mentor for 4 undergraduate students 2018 – 2019

*Global Health Systems Program, Western University, London, Canada*
Community partner for 4 graduate students 2019

*Western University’s Alternative Spring Break Program to Peru*
Faculty/graduate student team leader for 16 undergraduate student leaders 2018 – 2019

*Bangalore Baptist Hospital, India*
Fieldwork in-charge for a music therapy student from Louisiana, USA June – August 2013

RESEARCH EXPERIENCE

Research Assistant, Graduate Department of Health and Rehabilitation Sciences, Western University
Principal Investigator: Dr. Amanda Grenier
Project: Precarity and Aging
Funded by: McMaster University SSHRC grant
January – July 2019
Research Assistant, Graduate Department of Health and Rehabilitation Sciences, Western University  
Principal Investigator: Dr. Colleen McGrath  
Project: Participatory Action Research Project with Older Adults with Age-Related Vision Loss  
Funded By: Western University SSHRB Seed Research Grant  
March 2017–April 2018

Graduate Research Assistant, Children’s Participation and Environment Research Laboratory (CPERL), Colorado State University  
Principal Investigator: Dr. Mary Khetani  
Project: Young Children’s Participation and Environment Measure (YC-PEM) Validation Study  
Funded By: NIH K12 HD055931  
August 2013 – May 2015

PROFESSIONAL EXPERIENCE

Co-Founder, VisAbility Kenya, Machakos, Kenya  
Program: A volunteer-run, activity-based, initiative addressing the rights and inclusion of people with mental illness in Machakos, Kenya  
May 2017- Present

Advisor, Club Kodiak, Burks Falls, Canada,  
Clientele: Young Adults with Special Needs  
Summer, 2016

Occupational Therapist, Bangalore Baptist Hospital, India  
Program: Community-based Rehabilitation; Out-patient care; In-patient care  
Clientele: Worked primarily with children with disabilities and families; psychiatry; neurology  
August 2011 - August 2013

VOLUNTEER EXPERIENCE

Special Needs Volunteer, Harvest Bible Chapel, London, Canada  
Clientele: Children with special needs  
2016 – 2017

Occupational Therapy Student Grader, Western University, London  
Students: First year occupational therapy students  
October 2016

Volunteer Occupational Therapist, U&I, Bangalore, India  
Clientele: Boys and young adults with intellectual disabilities  
August 2011

Volunteer Occupational Therapist, Baptist Christian Hospital, Assam  
Clientele: Children with disabilities; Community workers  
August -Sept 2010

LEADERSHIP ROLES AND TRAINING

Student Executive, Global Health Equity Collective, Western University  
2018 – Present

Cultural Mentor and Orientation Leader, Colorado State University  
Leadershape Institute, Colorado State University  
2014 – 2015  
2014

General Secretary, Occupational and Physiotherapy Student’s Association, Christian Medical College, India  
2009 – 2010
PROFESSIONAL AFFILIATIONS

College of Occupational Therapists of Ontario 2016 – Present
Canadian Society of Occupational Scientists 2016 – Present
Canadian Association of Occupational Therapists 2016 – Present
World Federation of Occupational Therapists 2016 – Present
American Occupational Therapy Association 2014 – 2015
All India Occupational Therapy Association 2006 – Present

OTHER CERTIFICATES

San’yas Indigenous Cultural Safety Training, Provincial Health Services Authority in British Columbia (2018)