Enabling physical activity participation for children and youth with disabilities: A knowledge-to-action approach

CLAIRE EMILY WILLIS BSc (HONS)
I, Claire Willis, certify that:

This thesis has been substantially accomplished during enrolment in the degree.

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The research involving human data reported in this thesis was assessed and/or approved by the Princess Margaret Hospital Ethics Committee (2013099), the University of Western Australia Human Research Ethics Committee (RA/4/1/6556, RA/4/1/8263), and the Norwegian Regional Ethics Committee Section South East (2014/1342-1).

Written patient consent has been received and archived for the research involving patient data reported in this thesis.

This thesis contains published work and/or work prepared for publication, some of which has been co-authored.

PhD Candidate Signature

(Claire Willis)
DECLARATION FOR THESE CONTAINING PUBLISHED WORK AND WORK
PREPARED FOR PUBLICATION

This thesis contains published work and/or work prepared for publication, some of which has
been co-authored. The bibliographical details of the work are presented on the title page for each
paper, including a statement detailing the contribution of the PhD Candidate. The work involved
in designing the studies described was performed primarily by Claire Willis (candidate). The
thesis outline and experimental design was planned and developed by the candidate, in
consultation with Professor Catherine Elliott, Senior Lecturer Siobhan Reid, Associate Professor
Sonya Girdler, and Associate Professor Michael Rosenberg (the candidate’s academic
supervisors).

All participant recruitment and management was carried out by the candidate, Associate Professor
Reidun Jahnsen and Dr Astrid Nyquist (the candidate’s clinical supervisors in Norway). In
addition, the candidate was responsible for all data analysis. The candidate drafted the original
thesis chapters as well as papers arising from this thesis that have been published or prepared for
future publication. Professor Catherine Elliott, Senior Lecturer Siobhan Reid, Associate Professor
Sonya Girdler, Associate Professor Michael Rosenberg, Associate Professor Reidun Jahnsen, and
Dr Astrid Nyquist provided guidance on data collection, data analysis and all drafts associated
with the thesis until the examinable version was finalised.

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Coordinating Supervisor Signature

(Siobhan Reid)
The importance of physical activity and its promotion for all children and youth is well documented and indisputable. However, children and youth with disabilities participate in significantly less physical activity than their typically developing peers \(^1,2\), and display extraordinary levels of sedentary behaviour \(^3\). While exercise programs for children and youth with disabilities have become a contemporary focus of intervention, participation is typically measured as a secondary outcome, and there is limited demonstration of intervention effect on this domain \(^4\). Participation is optimally facilitated when participation preferences of the child \(^5\) and family \(^6\) are considered, and when the family is both supported \(^7\), and can provide support \(^6\). Furthermore, there is recognition that accessibility to and accommodation in community-based programs is important for long-term physical activity participation \(^8\). Yet, there is limited evidence of these considerations within interventions attempting to engage children and youth with disabilities in physical activity. It is unknown whether physical activity interventions that are family-centred, goal-directed, and community-focused, can enable and sustain participation in physical activity for children and youth with disabilities and their families.

Given the time and cost associated with the development, implementation and evaluation of effective interventions, adapting existing evidence-based programs may facilitate the efficient development of new (context-specific) interventions that are relevant, sustainable and acceptable to the target population \(^9\). Beitostolen Healthsports Centre (BHC) is a rehabilitation centre in Norway, seeking to enhance lifelong physical activity participation in local environments for people with disabilities. The term ‘healthsports’ is a national variant of the international term Adapted Physical Activity, and forms the foundation of programs and practice at BHC. The Centre is recognised as an official part of the Norwegian national health system in physical medicine and rehabilitation, providing services to approximately 500 children and youth and their families from around the nation each year. The Local Environment Model (LEM) was designed by researchers and staff at the centre in 2007 \(^10\). The model engages children, parents, professionals at BHC, and community-based service providers in the preparation, intensive intervention, and follow-up stages of service delivery \(^10\). Additionally, there is a focus on cooperation, education, and resource capacity building in partnership with communities to facilitate continued participation in a child’s local environment \(^10\). Although the LEM has been in operation for some time, a complete program evaluation has not taken place.

To comprehensively evaluate the LEM, and identify how and why the intervention works, this thesis applies the Medical Research Council’s complex interventions framework \(^11\) and the Canadian Institute of Health Research Knowledge-to-Action Cycle \(^12\). Consumers and the community were involved throughout this process, to identify the problem, determine knowledge
needs, and adapt new knowledge to a local context to facilitate selecting, tailoring and implementing a participation intervention for Australian children and youth with a disability.

The overarching aim of this research is to contribute to the evolving evidence surrounding participation in physical activity for children and youth with disabilities, to enhance the design and effectiveness of interventions attempting to optimise these outcomes. To address this, we have: (i) undertaken a scoping review to identify the elements of community-based programs that create meaningful participation experiences for children with disabilities, (ii) evaluated the LEM, an existing model of service, to determine whether the intervention enables children and youth with disabilities and their families to achieve their physical activity participation goals, (iii) examined how the intervention accomplishes this, from the perspectives of program staff, paediatric service providers in the community, and children and parents involved in the intervention, and (iv) involved consumers and the community in all studies, at various stages of the research process.

This doctoral thesis is written as a series of papers, each making a unique contribution and adding to the evidence base of enhancing participation outcomes for children and youth with disabilities. The opening paper presents a scoping review, synthesising the literature describing elements of community leisure programs that create meaningful participation experiences for children and youth with disabilities. This paper followed the updated recommendations of the original scoping review methodological framework. Studies describing the experience of participating in a community-based programme or activity from the perspectives of children and youth with a disability aged 0–21 or their parents, were included. Twenty articles were included, and ten elements contributing to meaningful participation experiences were identified. These revealed the substantial contribution of social interaction and relationships in creating and facilitating positive and engaging experiences for children and youth with disabilities. Knowledge derived from this review may assist practitioners when considering the core components of interventions that aim to optimise participation outcomes in community-based leisure activities. Consideration of these elements in relation to ongoing participation in physical activity is explored in Papers Two, Three, Four and Five of this thesis.

The second paper of this thesis examines whether the LEM enables children with disabilities (n=92) to achieve their physical activity participation goals. This paper employed a pre-test post-test quasi-experimental design to evaluate changes in performance, satisfaction and attainment of participation goals, and identified factors influencing participation in local community settings following the intervention. Significant improvements were observed following the intervention at BHC, and at 12 weeks follow-up outcomes remained significantly higher than at baseline.
These results provide evidence for goal-directed, family-centred interventions to optimise participation in physical activity in local environments for children and youth with disabilities.

Given the encouraging findings from Paper Two, it was important to answer the second question of complex intervention evaluation: how and why does the intervention work? Ethnographic methods were employed, having previously demonstrated utility in describing the process of change during an intervention \(^{16, 17}\). Papers Three, Four and Five describe these findings, from the perspectives of BHC staff and local paediatric service providers, children, and parents, respectively.

Paper Three identifies the active ingredients and operational definitions of the LEM from the perspective of service delivery \((n=20)\). Active ingredients are described in relation to intervention design, the environment, and the effect on the individual, and are linked to the International Classification of Functioning, Disability and Health. This paper describes components of an intervention that enables physical activity participation, promotion, and sustainability of practices for children and youth with disabilities. The accompanying operational definitions may promote consistency across practitioners at the level of actual service delivery in any future program implementation. Understanding program mechanisms and how they operate to improve outcomes is a required (and often neglected) step in advancing evidence-base practice. This is explored further in Paper Four and Five.

Paper Four aimed to determine the association between context, mechanisms and outcome(s) of the LEM intervention, based on the perceptions and behaviours of children and youth with disabilities and their parents \((n=75)\). Using realist evaluation, this paper developed a refined program theory and identified the configuration of features that enabled children and youth with disabilities to participate. Whilst optimising participation in physical activity is a primary outcome of the LEM, the findings of this study demonstrate that outcomes for children and youth extended beyond this. This theory integrates mechanisms and context to forecast and explain outcome patterns, and we encourage further testing and utilisation by policy makers, researchers and practitioners across interventions and services.

The fifth paper of this thesis aimed to describe the experience of parents \((n=44)\) in the LEM intervention. A grounded theory approach was used for this study, which enabled the research question to become progressively more focused as parents described a journey of becoming facilitators of their child’s participation. The thematic concepts uncovered in this study construct a theory describing a social process of parent learning and empowerment. This study describes novel findings that illustrate how parents can be empowered to embody facilitative roles, and
presents a theoretical framework that may be used in future family-centred interventions to enable a child’s participation in physical activity.

Involving relevant stakeholders throughout the research process has been identified as a key knowledge translation strategy. Paper Six examines the impact of involving consumers and the community across all stages of this thesis. In addition to detailing the impact and associated outcomes, this paper identifies processes and contexts that facilitated these. This study reports clear evidence that consumer involvement can enhance the quality of research, ensure the relevance of results to the target group, and accelerate the dissemination and implementation of findings.

The outcomes of this research have significant implications for the development of interventions that aim to improve participation outcomes for children with disabilities. This thesis adds new knowledge regarding the optimisation of participation in physical activity through goal-directed and family-centred interventions for children with disabilities. Of importance, how this transpires is explored from the perspectives of staff, service providers, parents and children involved in the intervention, detailing the active ingredients, program mechanisms and contexts that promote meaningful outcomes. Together, these studies have linked each stage of the research process within the context of consumer-determined priorities, to provide a cumulative understanding of how and why an existing model of service enables children and youth to achieve physical activity participation goals. It is hoped that this will support the development of more effective interventions, and encourage their application across settings to improve outcomes for children and youth with disabilities.
Table A. An overview of the methods used in each of the papers in this thesis

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| Sample | 20 studies included for review | 92 children with a range of disabilities (11y 1m, sd 2y 8m; 49 males), and their parents (n=92) | 13 staff from BHC 7 community-based service providers | 31 children (12y 6m SD 2y 2m; 18 males) and their parents (n=44, 26 mothers, 18 fathers) | 44 parents (26 mothers, 18 fathers) | 9 stakeholders, including consumers. |

| Data collection | Database searches of Medline, Embase, PsycINFO, ERIC, SportDiscus, CINAHL, Scopus and Web of Science | Child and parent-rated COPM pre- (T1), post-intervention (T2), and 12 weeks follow-up (T3). GAS assessed T2-T3. Qualitative inquiry T3 | Participant observation (n=20) Interviews (n=15) Focus groups (2) (n=5) | Participant observation (n=75) Interviews: Parents (n=18) Children (n=5) Focus groups (2) Children (n=11) | Participant observation (n=44) Interviews: Parents (n=18) Documentation of 5 focus-group style meetings held over 24 months, and all products arising from this |

| Data analysis | Quantitative data: Descriptive statistics Qualitative data: Meta-ethnography | Quantitative data: Friedman tests, post hoc Wilcoxon signed-rank tests with Bonferroni correction Qualitative data: Framework approach informed by ICF:CY Inductive open coding and thematic analysis ICF:CY linkage | CMO framework analysis and CMO linkage | Open, axial, and selective coding | GRIPP framework analysis of documents |

COPM, Canadian Occupational Performance Measure; GAS, Goal Attainment Scale; BHC, Beitostolen Healthsports Centre; ICF:CY, International Classification of Functioning, Disability and Health: Child and Youth version; CMO, context-mechanism-outcome; GRIPP, Guidance for Reporting Involvement of Patients and the Public.
References


Acknowledgements

By pure chance, or perhaps a twist of fate, I discovered a rehabilitation centre in the middle of the mountains in Norway. It was there this all began; an idea, that evolved into a once-in-a-lifetime journey, and now a PhD thesis.

Experiences are shaped by the people that you share them with, and I have been so incredibly lucky to be surrounded by some of the worlds’ greatest. I have an unbelievably talented and dedicated supervision team of academics, clinicians, and public health advisors that span across the world. Thank you for making this a possibility.

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when things felt a little out of reach. Thank you for your expertise, and for joining me that first time in Norway – you have certainly never looked back!

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**Dr Anna Gubbay, Dr Jane Valentine, Dr Noula Gibson, Dr Kate Langdon, and Ria Ryan;** Thank you for your overwhelming level of support for this research, and for the Exercise and Health Promotion Service at Princess Margaret Hospital. Thank you for your belief and confidence in my vision and my abilities; being apply to apply the best available evidence directly into clinical practice has enabled some highly meaningful outcomes for children and their families. **Anna Thetford,** it has been a privilege to coordinate this service with your guidance and support. **Mathew Hyde.** It’s always the beginning of greatness when you meet someone who shares your vision. Thank you for it all.

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Publications and Abstracts

The following is a list of publications and abstracts to which I have contributed during the course of my candidature, arising both directly and indirectly from this thesis.

Peer reviewed publications


Peer reviewed publications submitted to journal (for review)


**Peer reviewed conference abstracts**


*Finalist for Top Paper Award*


*Winner of the MindLink Brightwater Interdisciplinary Focused Research Award

Invited Presentations

Invited speaker on ‘Working in Multidisciplinary Teams in Paediatric Rehabilitation’, for 4th year exercise rehabilitation students at The University of Western Australia, October 2016, Perth Australia.

Invited chairperson for ‘The Neurological Lived Experience’, postgraduate education series for 4th year exercise rehabilitation students at The University of Western Australia, September 2016, Perth Australia.

Invited speaker on ‘Paediatric Exercise Rehabilitation’, for the Exercise and Sport Science Australia Western Australian 2015 Symposium, Perth Australia.


Guest lecturer on ‘Goal Setting in Paediatric Exercise Rehabilitation’, for 4th year exercise rehabilitation students at The University of Western Australia, August 2015, Perth Australia.

Awards

2016: Western Australian Young Achiever Award (Health and Wellbeing), Awards Australia.
2016: Conference Scholarship, Australian Academy of Cerebral Palsy and Developmental Medicine.
2016: Continuing Education Scholarship, Centre of Research Excellence for Cerebral Palsy.
2014:  MindLink Brightwater Interdisciplinary Focussed Research Award, Australasian Society for the Study of Brain Impairment.
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**Grants**


**Clinical experience**

Whilst completing my PhD, I worked as an Accredited Exercise Physiologist 0.2 FTE on behalf of the Department of Paediatric Rehabilitation, Princess Margaret Hospital for Children.
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<td>APA</td>
<td>Adapted Physical Activity</td>
</tr>
<tr>
<td>BHC</td>
<td>Beitostolen Healthsports Centre</td>
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<tr>
<td>BHSS</td>
<td>Beitostolen Healthsports Centre</td>
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<tr>
<td>C</td>
<td>Context</td>
</tr>
<tr>
<td>CAPE</td>
<td>Children’s Assessment of Participation and Enjoyment</td>
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<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
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<tr>
<td>CHF</td>
<td>Consumer Health Forum</td>
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<tr>
<td>CIHR</td>
<td>Canadian Institute of Health Research</td>
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<tr>
<td>CMO</td>
<td>Context-Mechanism-Outcome</td>
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<tr>
<td>CMOc</td>
<td>Context-Mechanism-Outcome configuration</td>
</tr>
<tr>
<td>CoP</td>
<td>Communities of Practice</td>
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<tr>
<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
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<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>DAMP</td>
<td>Deficiency in attention, motor control and perception</td>
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<tr>
<td>DCD</td>
<td>Developmental Coordination Disorder</td>
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<tr>
<td>fPRC</td>
<td>Family of Participation-Related Constructs</td>
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<tr>
<td>GAS</td>
<td>Goal Attainment Scale</td>
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<tr>
<td>GMFCS</td>
<td>Gross Motor Function Classification System</td>
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<tr>
<td>GRIPP</td>
<td>Guidance for Reporting Involvement of Patients and Public</td>
</tr>
<tr>
<td>I</td>
<td>Inclusive</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<tr>
<td>ICF:CY</td>
<td>International Classification of Functioning, Disability and Health: Child and Youth Version</td>
</tr>
<tr>
<td>ID</td>
<td>Intellectual Disability</td>
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<tr>
<td>k</td>
<td>Frequency</td>
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<td>Local Environment Model</td>
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<td>Local Paediatric Service Providers</td>
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<td>Mechanism</td>
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<td>Medical Research Council</td>
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<td>n</td>
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<td>Not covered-health condition</td>
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<td>NGOs</td>
<td>Non-Government Organisations</td>
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<tr>
<td>Abbreviation</td>
<td>Definition</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>NS</td>
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<td>NSF</td>
<td>National Sports Federation</td>
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<td>Outcome</td>
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<td>PAC</td>
<td>Preferences for Activities of Children</td>
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<td>PD</td>
<td>Physical Disability</td>
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<td>pf</td>
<td>Personal Factors</td>
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<td>Princess Margaret Hospital for Children</td>
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<td>PMHF</td>
<td>Princess Margaret Hospital Foundation</td>
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<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
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<td>S</td>
<td>Segregated</td>
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<td>SD</td>
<td>Standard Deviation</td>
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<td>SDT</td>
<td>Self-Determination Theory</td>
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<td>SEAS</td>
<td>Self-report of Experiences in Activity Settings</td>
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<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
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<tr>
<td>UWA</td>
<td>University of Western Australia</td>
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</table>
Chapter One

INTRODUCTION

1.1 INTRODUCTION

Participation is defined as ‘involvement in a life situation’ \(^1\), and is a fundamental right of all children \(^2\). Participation is a core component of the International Classification of Functioning, Disability and Health Child and Youth Version (ICF-CY), a universally recognised framework utilised to assess health and health-related outcomes, design and evaluate interventions and services, and develop policies for children and youth \(^3\). The use of participation as a classifying parameter of the ICF-CY, and its conformity with international conventions and declarations on behalf of the rights of children everywhere \(^2, 4\), highlights its profound role in child health, development, and well-being \(^3\). As such, enabling participation is often described as the ultimate outcome in health interventions \(^5\).

Since the introduction of the ICF \(^1\) and ICF-CY, participation outcomes of children and youth with disabilities have received considerable attention. However, limited clarity surrounding the conceptualisation and operation of the construct has resulted in disparities in definitions of participation, varied approaches to measurement, and imprecision and confusion surrounding research findings \(^6\). As the ICF and the ICF-CY do not clearly distinguish activity and participation within the classification system, this has resulted in diverse interpretation and operationalisation of this construct \(^5, 7, 8\). In an attempt to streamline this, the Family of Participation-related Constructs (fPRC) describes participation as two elements: attendance and involvement \(^6, 9\). Attendance, defined as ‘being there’ and measured as frequency and/or diversity of activities in which an individual takes part, is a necessary prerequisite to involvement. Involvement describes the experience of attending, and may include elements of engagement, motivation, and social connection \(^6\). While related concepts of preference, activity competence, and sense of self are distinct from the participation phenomenon, the activities that children attend must accommodate these if they are to be experienced as meaningful \(^6\). As participation has predominantly been operationalised as ‘attendance’ \(^10\), there is limited understanding of the meaning of the experience of participating in activities in any life setting of a child. This additional information is critical for assessing the needs and outcomes of children and youth with disabilities and their families.

It is well documented that a child’s participation is influenced by all components of the ICF-CY. Growing in recognition is the role of the environment in explaining factors affecting participation.
in children and youth with disabilities \textsuperscript{11-13}. A recent scoping review indicated that all aspects of the environment operated as a barrier, as a facilitator, or both, to participation of children and youth with various types of disabilities \textsuperscript{11}. This is further supported in a qualitative meta-synthesis from the perspectives of youth themselves \textsuperscript{14}. Of interest, it has been identified that the community setting, as opposed to the home and school, was the context in which the environment played a more substantial role \textsuperscript{12}. As participation is intimately linked to context (i.e. ‘participation in what?’), an understanding of different environmental and contextual settings is needed to further our knowledge of the nature, variability, and outcomes of attendance and involvement \textsuperscript{9, 15}.

Participation in leisure activities is associated with positive physical, psychological and social outcomes for children and youth both with and without disabilities \textsuperscript{13, 16}. An evidence synthesis examining this setting described that children and youth with disabilities participate more often in informal activities, participate with family more often than with peers, and are particularly limited in active-physical participation in activities outside of school \textsuperscript{17}. Empirical evidence \textsuperscript{17} and consumer priorities \textsuperscript{18} advocate the need to develop interventions that may assist in improving these outcomes, which has been met with some success \textsuperscript{19, 20}. Recent approaches attempting to improve participation outcomes for youth in leisure settings were directed at ameliorating environmental factors, demonstrating to be feasible and effective \textsuperscript{20-22}. As all interventions were conducted as feasibility studies, authors subsequently encouraged the use of environment-focussed interventions across larger participant samples \textsuperscript{20-22}.

A concerning finding across literature describing participation in leisure activities is the low levels of participation in physical activities that children and youth with disabilities partake in \textsuperscript{17, 23}. This aligns with research specifically investigating physical activity patterns in children and youth with disabilities, describing significantly less participation than their typically developing peers \textsuperscript{24, 25}, and alarming rates of sedentary behaviour \textsuperscript{26}. The importance of physical activity and its promotion for all children and youth is well documented and indisputable. Encouragingly, exercise programs for children and youth with disabilities have become a contemporary focus of intervention, producing beneficial outcomes across a range of populations \textsuperscript{27-29}. However, these outcomes are only partially maintained at follow-up \textsuperscript{28, 30}, and there is little evidence that exercise programs (whereby participation is typically measured as a secondary outcome \textsuperscript{31}), enhance physical activity participation outcomes \textsuperscript{30, 31}. It is evident that training interventions alone are not enough for children and youth (with and without disabilities) to stay physically active \textsuperscript{32-34}.

There is a paucity of literature describing interventions primarily targeted at enhancing participation in physical activity for children and youth with disabilities. A recent randomized controlled trial (RCT) found that a six month physical activity stimulation program, including motivational interviewing, home-based physical therapy, and fitness training, did not increase the
physical activity levels of children with cerebral palsy compared to a regular therapy control group. While there is recognition that accessibility to and accommodation in community-based physical activity programs is important for long-term physical activity participation, there was limited evidence of this within the intervention design. Furthermore, it has been suggested that participation is best supported when the child’s participation preferences are considered, and when the family is both supported, and can provide support. Physical activity interventions that are family-centred, goal-directed, and consider community resources, may therefore be effective at optimising participation and fostering long-term outcomes for children and families. An understanding of how to develop and evaluate interventions is essential for their effectiveness and implementation into clinical practice.

Complex interventions are widely used in health services, defined as interventions with several interacting components. In 2008, the Medical Research Council (MRC) released an updated guide for the development and evaluation of complex health interventions. The original guidelines are recognised internationally, and were designed to help researchers choose and implement appropriate methods for design and evaluation of interventions. The updated guidelines re-emphasise some of the key messages, and assign due weight to the development and implementation phases, as well as to evaluation. Importantly, it provides a more flexible model of the process; from development through to implementation, a complex intervention may take a range of different forms, and often these will not follow a linear or cyclical sequence. Figure 1.1 summarises the main stages and the key functions and activities at each stage.

![Figure 1.1 Key elements of the development and evaluation of complex interventions](image)

Developing an intervention should begin by identifying the relevant, existing evidence base, and conducting a review of the literature. It is also necessary to develop a theoretical understanding of the likely process of change, by drawing on existing evidence and theory, and supplementing this with new primary research. This should be done for both the development of an
intervention, and the evaluation of an intervention that has already been developed and/or implemented. Awareness of relevant theory is more likely to result in an effective intervention than a purely empirical or pragmatic approach. In evaluating a complex intervention, the primary question is whether the intervention works. A second key evaluation question is how the intervention works, i.e. what are the active ingredients of the intervention and how are they operationalised? It is only by addressing this question that we can develop a cumulative understanding of causal mechanisms, design more effective interventions, and apply them appropriately across groups and settings.

As suggested by the MRC framework, implementation needs to be considered in the early stages of intervention development. One of the most promising strategies for effective implementation is the involvement of consumers and the community in the research process. Linking consumer priorities and perspectives within research supports the development of interventions that are relevant to the needs of the target group, supporting their ultimate success. Of relevance, it has been reported that parents of children with disabilities in Australia ranked ‘participation research’ as their second most important research priority, after ‘prevention of their child’s condition’. In developing interventions that address this, it is imperative to ensure that the consumers and other key stakeholders are actively consulted throughout the research process to improve the quality and impact of research and to enhance the translation of outcomes.

1.2 Statement of the Problem

Currently, the literature contributing to the development and evaluation of interventions to optimise participation outcomes for children and youth with disabilities has largely been centred on (i) identifying the evidence-base for development and assessing feasibility and pilot testing of methods. As outlined by the MRC, these are important steps in the overall process. The only RCT primarily targeting physical activity participation did not demonstrate change in these outcomes, with limited exploration of causal mechanisms or contextual factors associated with variation in outcomes. Further research is required in identifying and/or developing theories, understanding why effective interventions work, and developing methods that incorporate implementation processes from the outset of research, if we are to develop, evaluate and translate effective interventions into practice.

Beitostolen Healthsports Centre (BHC) is a rehabilitation centre in Norway, seeking to enhance lifelong participation in local environments for people with disabilities by means of adapted physical activity (APA). The paediatric program at BHC is based upon a Local Environment Model (LEM, Appendix A), designed by researchers and staff at the centre in 2007. The model engages children, parents, professionals at BHC and local service providers in the preparation,
intensive intervention and follow-up stages of service delivery. Additionally, there is focus on cooperation, education and resource capacity building in partnership with local communities to facilitate continued participation in a child’s local environment. Although the LEM operates on a national level (i.e. children and families from all over Norway access the service), a complete program evaluation has not taken place. Given the time and cost associated with the development, implementation and evaluation of effective interventions, adapting existing evidence-based interventions may facilitate the efficient development of new (context-specific) interventions that are relevant, sustainable and acceptable.

While the MRC framework outlines an implementation phase, this is not described in sufficient detail to address all steps required for the implementation of evidence-based practice. Implementation is defined as the execution of the adoption decision, when the research is put into practice. A required key step within implementation is knowledge translation. The primary purpose of knowledge translation is to address the gap between what is known from research and knowledge synthesis, and the implementation of this knowledge to improve health outcomes.

The Canadian Institute of Health Research (CIHR) defines knowledge translation as ‘a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system’. To address the many multifaceted barriers associated with knowledge translation and program implementation, the CIHR have proposed the Knowledge-To-Action Cycle. The Knowledge-To-Action Cycle comprises the Knowledge Funnel (the process through which knowledge is refined, distilled, and tailored to the needs of knowledge end-users), and the Action Cycle (the process by which knowledge is implemented).
This thesis will apply the MRC complex interventions framework within the Knowledge Funnel of the Knowledge-To-Action Cycle, to evaluate the existing LEM intervention, and identify how and why the intervention works. This thesis will engage consumers and the community throughout this process, to identify knowledge needs, and adapt identified knowledge to a local context, to facilitate the implementation of an intervention that may optimise physical activity participation outcomes for children and youth with a disability.

1.2.1 STUDY AIMS

The overarching aim of this research is to contribute to the evolving evidence surrounding participation, to improve the design and effectiveness of interventions to enhance these outcomes for children and youth with disabilities. More specifically, this research aims to; (i) evaluate an existing model of service that may enable participation in physical activity for children and youth with disabilities, (ii) identify the active ingredients of the intervention from the level of service delivery, (iii) understand the relationship between intervention mechanisms and context that promote outcomes for children and youth with disabilities, (iv) explore the experience of parents in the intervention, and (v), describe the impact of involving consumers and the community in the evaluation and development of complex interventions.
1.2.2 RESEARCH SIGNIFICANCE

Globally, there is a need to encourage and enable greater participation in physical activity. To date, attempts to address this for children and youth with disabilities are centred largely on exercise interventions that have demonstrated little effect on this outcome. This thesis provides a rationale for family-centred, goal-directed, and community-focused interventions to optimise participation in physical activity for children and youth with disabilities. The participation-based intervention evaluated in this research attempts to enhance outcomes using activities that are meaningful to the child and family, and address aspects of context and the environment that may enable participation. As interventions alone are not enough for children and youth to stay physically active, this research will identify evidence of effective strategies that may facilitate ongoing participation in physical activity. This research will address key stages in the MRC complex interventions framework that are currently unexplored; developing theories, investigating processes, and incorporating implementation processes from the outset of research (guided by the Knowledge-To-Action Cycle), that may enhance physical activity participation outcomes for children and their families. This research will add new knowledge to our current understanding of:

1. The experience of children and youth with disabilities in community programs.
2. The evaluation of physical activity interventions using participation as a primary outcome measure.
3. Active ingredients of interventions, and their relationship to context and the environment, that promote meaningful outcomes.
4. Strategies that may encourage parents to become facilitators of a child’s participation in physical activity.
5. Methodologies that enable the identification of active ingredients of interventions, and development of related theory in childhood disability research.
6. Process, context, impact and outcomes of engaging consumers and the community in disability research.

This research will outline directions for future research, strategies to guide future intervention development, and generate knowledge products to address the needs and influence the practice of knowledge-users. The use of evidence-based knowledge translation strategies (including a knowledge translation plan, Appendix B) may optimise the uptake of this research within the community, provide more effective services, and enhance physical activity participation and quality of life for children and youth with disabilities and their families.
1.3 Thesis Outline

The introduction establishes the subject matter and context for this thesis, conveys the research problem, and details the approaches taken to answer the question. This thesis is presented as a series of individual papers addressing six separate but interrelated research questions. Each paper addresses specific components of the aforementioned MRC complex interventions framework and CIHR Knowledge-To-Action Cycle. The first paper presents a scoping review of literature regarding elements that contribute to meaningful participation in community-based leisure programs for children and youth with disabilities. This study also provides some background information for the participation focus of this thesis. The second paper details the outcomes of the LEM intervention relating to physical activity participation goal attainment, performance, and satisfaction for children and youth with disabilities and their parents. This paper also explores the factors affecting goal attainment in community settings following the intervention. In order to understand how the LEM intervention facilitates physical activity participation for children and youth with disabilities, the third paper identifies the active ingredients and operational definitions from the perspectives of those delivering the intervention. To understand this from the perspectives from those receiving the intervention, the fourth paper describes the relationship between mechanisms, context, and child-related outcomes according to children and their parents, and the fifth paper explores the experience of parents and related outcomes throughout the LEM intervention. Lastly, the sixth paper outlines the impact and outcomes of consumer involvement throughout varying stages of the research process in all papers in this thesis, and the processes and context that facilitated this. The series are followed by detailed appendices, including one additional related paper published by the candidate on barriers and facilitators to participation for families with children with disabilities in Western Australia (Appendix A; Thompson, Elliott, Willis et al., 2016), a detailed description of the LEM intervention (Appendix A; Nyquist, Willis, Elliott et al., submitted 2016), knowledge translation supplements (Appendix B), the quality appraisal checklist used in the scoping review (Appendix C), ethics approvals from all relevant institutions (Appendix D), and study information and consent forms (Appendix E). As each paper in this thesis stands alone, references are provided at the conclusion of each individual paper. The thesis concludes with a synthesis of results and discussion.

1.3.1 Chapter Two – Paper One

Elements Contributing to Meaningful Participation for Children and Youth with Disabilities: A Scoping Review

The aim of this paper is to:
• Examine the extent, range and nature of research that describes the elements contributing
to meaningful participation experiences in community activities for children and youth
with disabilities, with a view to summarise, synthesise and disseminate findings to inform
future interventions and research methodologies.

1.3.2 Chapter Three – Paper Two

Enabling Physical Activity Participation for Children with Disabilities Following a Goal-
directed, Family-Centred Intervention

The aims of this paper are to:
• Evaluate change in physical activity participation following a goal-directed, family-
centred intervention in children and youth with a disability immediately post-intervention
and at 12 weeks follow-up.
• Explore the factors affecting goal attainment in a child’s local environment following
intervention, as reported by the parent.

In regards to the first aim, it is hypothesised that:
• The intervention will increase perceived (parent and child) performance and satisfaction
of individual physical activity participation goals post intervention and at 12 week follow
up.
• Children will attain goals relating to physical activity participation in their local
community set post-intervention.

As this paper utilises a qualitative methodology, no hypotheses are presented for the second aim,
but rather a research question:
• What are the factors that affect a child’s goal attainment in their local environment
following the intervention, from the perspective of parents?

1.3.3 Chapter Four – Paper Three

‘Capturing the Magic’: Identifying the Active Ingredients of a Physical Activity Participation
Intervention for Children and Youth with Disabilities

The aims of this paper are to:
• From the perspectives and practices of staff at BHC and visiting paediatric service
providers, define the active ingredients by which the intervention may facilitate change.
• Develop operational definitions of these ingredients to support implementation in other
settings.
As this paper utilises a qualitative methodology, no hypotheses are presented, but rather research questions:

- From the perspectives and practices of staff at BHC and visiting paediatric service providers, what are the active ingredients of the intervention that facilitate change?
- What are the operational definitions of these ingredients that will support implementation in other settings?

1.3.4 Chapter Five – Paper Four

What works, for whom, in what circumstances, and how? A Realist Evaluation of a Physical Activity Participation Intervention for Children and Youth with Disabilities

The aims of this paper are to:

- From the perceptions and behaviours of the program participants, determine the association between context, mechanism and outcome(s).
- Develop a refined program theory to inform future practice and policy surrounding similar interventions.

As this paper utilises a qualitative methodology, no hypotheses are presented, but rather research questions:

- From the perceptions and behaviours of the program participants, what is the association between context, mechanism and outcome(s)?
- What is the refined program theory that will inform future practice and policy surrounding similar interventions?

1.3.5 Chapter Six – Paper Five

Facilitating Participation in Physical Activity for Children with Disabilities: A Theory of Parent Learning and Empowerment

The aims of this paper are to:

- Describe the experience of parents of children with disabilities participating in the LEM intervention

As this paper utilises a qualitative methodology, no hypotheses are presented, but rather a research question:

- What is the experience of parents of children with disabilities participating in the LEM intervention?
1.3.6 Chapter Seven – Paper Six

Involving Consumers and the Community in Paediatric Disability Research: Impacts, Outcomes, Processes, and Context

The aims of this paper are to:

- Describe the impact and outcomes of consumer involvement in the research project.
- Examine the process(es) and context(s) of consumer involvement in the research project that foster the impact and outcomes.

As this paper utilises a qualitative methodology, no hypotheses are presented, but rather research questions:

- What is the impact and outcomes of consumer involvement in the research project?
- What process(es) and context(s) of consumer involvement in the research project foster the impact and outcomes?

1.3.7 Chapter Eight – Summary of Findings and Conclusion

The final chapter aims to provide an overall synthesis of results presented throughout the thesis, integrating the major findings from each study and its contribution to paediatric disability literature. It will highlight the broader conclusions of the research in the context of consumer and community needs and research priorities, and provide guidelines for future research directions and recommendations for clinical practice.

1.3.8 Thesis as a Series of Papers

The University of Western Australia supports the submission of PhD theses that comprise a series of papers prepared for publication. This structure has been adopted by the candidate in the submission of this thesis. As such, while the theoretical linking between the studies (i.e. papers) should be made clear for the examiner, each study must be stand-alone in content. Consequently, theses adopting a series of papers approach sometimes result in repetition of methodology from study to study. Please note that where possible reference to previous papers (i.e. previous studies) has been undertaken, however at times the examiner may find some repeated methodology redundant in the course of reading.
1.4 LIMITATIONS AND DELIMITATIONS

There are a number of limitations that should be acknowledged when interpreting the results of this research. The LEM is based on the child’s individual goals, developed with the assistance of an allied health professional and the parent using the Canadian Occupational Performance Measure \(^{49}\) and Goal Attainment Scale \(^{50}\). The intervention is developed by the administering health professionals, according to the children’s individual goals within each group. Subsequently, goal focus and the type of activities delivered in the intervention were not the same between each LEM participant group across Chapters Three to Six. However, the dosage of intervention was the same between all LEM groups. As there was no control group within the study design in Chapter Three, it is not possible to separate the outcomes of intervention from other influencing effects.

Due to the qualitative nature of Chapter Four to Six, the findings cannot be generalised to all children with disabilities, or all parents of children with disabilities. This is however, reflective of the involvement descriptor of participation; the meaning of experience is individually-derived \(^{6}\). Further, this research was conducted in one rehabilitation centre in one country. Evaluations and perspectives of professionals and families involved in other centres that may exist may have broadened the scope of information provided. Despite these limitations, the large participant samples, application of methods of trustworthiness, and multiple levels of data analysis add weight to the findings of the studies.

This research is delimited by the inclusion of children and youth aged 6-17 years, the age of children eligible to participate in the LEM. Inclusion criteria in Chapter Five and Six also specified that only the primary caregiver(s) could participate. This was applied so to gain an understanding of the perspectives of participants who were the most informed about a child’s participation needs, goals, and experiences, and of whom their own concerns, actions and behaviours may have directly affected the child’s participation. Further, in the interpretation of data in Chapter Four to Seven, alternative theoretical perspectives could have been adopted. Subsequently, in all of these papers we encourage further exploration, investigation, and/or testing of our research questions, hypotheses and theories.
1.5 REFERENCES


Chapter Two

Elements contributing to meaningful participation for children and youth with disabilities: a scoping review

This manuscript was accepted for publication in *Disability and Rehabilitation*, in July 2016; Willis CE, Girdler, S, Thompson, M, Rosenberg, M, Reid, S.L., and Elliott, C. Elements contributing to meaningful participation for children and youth with disabilities: A scoping review. *Disabil Rehabil* 2016. doi: 10.1080/09638288.2016.1207716.

The full, published paper is available at: http://dx.doi.org/10.1080/09638288.2016.1207716

The PhD candidate, Claire E Willis, accounted for 90% of the intellectual property associated with the final manuscript (the primary individual involved in the review design, database searches, data extraction, analysis and interpretation, and manuscript preparation and revision). Collectively, the remaining authors contributed 10%. The formatting and references of this chapter follow the guidelines for submission to *Disability and Rehabilitation*. 
The first paper presented in this thesis is a scoping review of literature relating to the ‘involvement’ element of participation for children and youth with disabilities. Whilst a significant body of research describes the frequency, range and predictors of participation in activities outside-of-school (i.e. attendance), there is limited understanding of a child’s experience of attending. Understanding optimal experiences and environments in these settings is required for the design of interventions that promote and facilitate ongoing participation. This may be of particular significance for interventions directed at optimising physical activity participation, as accommodation in community-based programs is recognised as important for promoting long-term outcomes. This paper aimed to synthesise literature describing elements contributing to meaningful participation experiences in community leisure activities in children and youth with disabilities, to inform future interventions and research methodologies. In doing so, this paper identifies gaps in the current literature and provides directions for future research, some of which is carried out in subsequent chapters of this thesis.
2.1 Abstract

Purpose: To synthesise research literature describing elements of community recreation and leisure activities that create meaningful participation experiences for children and youth with disabilities.

Method: Database searches of Medline, Embase, PsycINFO, ERIC, SportDiscus, CINAHL, Scopus and Web of Science were conducted. Studies describing the experience of participating in a community-based program or activity from the perspectives of children and youth with a disability aged 0-21 or their parents, and published in English were included. Meta-ethnography was used to synthesise qualitative data, and resulting themes were conceptualised in the ICF-CY. Consultation with stakeholders occurred throughout the review process.

Results: The search identified 9,544 articles, of which 20 were included for review. Ten elements contributing to meaningful participation experiences were identified and organised as; person-based elements (n=5: having fun, experiencing success, belonging, experiencing freedom, developing an identity); environment-focused elements (n=4: authentic friendships, the opportunity to participate, role models, family support), and; activity-related elements (n=1: learning).

Conclusions: Elements contributing to meaningful leisure participation are interrelated. This review reveals the substantial contribution that meaningful interactions and relationships have in creating and facilitating positive and engaging experiences. Outcomes of this review may assist professionals in the design of targeted interventions to facilitate leisure participation.
2.2 INTRODUCTION

‘Through participation, we acquire skills and competencies, connect with others and our communities, and find purpose and meaning in life’ [1].

Participation is a goal shared by children, parents, clinicians and service providers involved in paediatric rehabilitation. Ultimately, we strive to enable participation in all life settings of a child, to facilitate outcomes that are of importance to both children and their families. Yet, participation can be complex to facilitate and achieve. It is both a multidimensional and evolving phenomena, with the interaction of personal and environmental factors occurring simultaneously over time. As such, developing and implementing interventions that produce significant, long-term outcomes is challenging [2]. This scoping review aims to describe the elements that should be considered when designing and implementing programs and interventions to enhance community participation for children and youth with disabilities.

Since its introduction in 2001, the International Classification of Functioning, Disability and Health (ICF) has had a significant impact on the conceptualisation and measurement of participation of children with disabilities [3]. With the adoption of the ICF in rehabilitation research, we have a globally agreed on structure and common language that can be used to guide the translation of knowledge into clinical practice [3]. The ICF defines participation as ‘involvement in life situations’, and is operationalised as ‘the execution of a task in a current environment’ [3]. Subsequently, a significant body of empirical research has demonstrated the frequency, range and predictors of participation in activities outside of school in children with disabilities [4-9]. These objective indicators are important in identifying areas of need and difference within populations, and are useful in undertaking the large scale assessments necessary in the validation of outcomes that can then guide service provision and policy development.

However, participation is not exclusively about the number of activities a child participates in, or how often they attend that activity; to participate, involvement in any life situation must be associated with meaning [10]. Arguments for the development of a third qualifier of the subjective aspects of participation within the activity and participation domain of the International Classification of Functioning, Disability and Health-Child and Youth version (ICF-CY) are increasing, to enable a more holistic view of this construct [10, 11]. To conceptualise this, Palisano et al. [12] defined optimal participation as ‘a subjective, personally determined construct, related to the meaning that is associated with and derived from an individual’s physical, social and self-engagement in activity and life situations’ [12 p. 1042]. The conceptualisation of optimal participation as ‘meaningful participation’ suggests that this meaning must be defined by the individual, and the context of participation [12, 13].
Participation in out-of-school activities is associated with positive physical, psychological and social outcomes for children and youth both with and without disabilities [14, 15]. Tonkin et al. [16] described that children and youth with disabilities participate more often in informal activities, participate with family more often than with peers, and are particularly limited in active-physical participation in activities outside of school. Systematic syntheses of current evidence highlight that participation in activities outside of school is influenced by factors at all levels of the ICF [7, 16, 17], with special focus on the impact of the environment [18]. Understanding the qualities of optimal environments [19] may therefore be crucial if we wish to engage children and youth with disabilities in positive participatory experiences in leisure activities in the community. In typically developing youth, Eccles and Templeton [20] have identified the essential elements that should underpin community-based programs in order to engage and support positive development. This literature supports current strengths-based approaches to an individual’s health and functioning [3, 21], and acknowledges the role of supportive relationships and environments in increasing positive outcomes [18].

In addition to the facilitative attributes of recreation and leisure settings, meaningful activity engagement and experiences are also necessary for positive development [20]. For typically developing youth, Eccles et al. [22] identified the mechanisms underlying optimal activity experiences as the opportunity to engage in challenging activities, engage with others, and to develop a sense of positive identity. Our understanding of the mechanisms underpinning optimal activity experiences for youth, both typically developing and those with disabilities, has been facilitated by the Self-report of Experiences in Activity Settings (SEAS) developed by King et al. [23]. The SEAS provides a retrospective view of youths’ experiences of activities within a variety of community and home activity settings [23]. Prior to the development of the SEAS, no other measures of activity participation captured the experiences of psychological engagement and meaningful experiences in the community for youth with disabilities. Currently, no measure exists for children. The absence of such a measure has restricted the scope and extent of research in this field, and has limited our ability to truly understand the participation experiences of children with disabilities.

In therapy settings, it is well recognised that understanding the clients’ views and priorities are an essential element in increasing engagement and participation [24, 25]. In paediatric rehabilitation, understanding the motivational processes behind activity engagement assists therapists in successfully addressing the needs of the child [26]. Fundamentally, for a child to be engaged, the activity must be meaningful [26]. Whilst a large body of empirical evidence exists regarding the determinants of participation in community activities of children with disabilities, there is less understanding of the elements which contribute to meaningful participation experiences in these settings. A recent evidence synthesis by Powrie et al. [27] was the first to systematically review
literature relating to the meaning of leisure for children and young people with physical disabilities. This review identified themes that resonated with the psychological needs of autonomy, relatedness, and competence, and highlighted social context as a consideration for leisure participation interventions [27]. Whilst this review provided novel insights into the meaning of leisure participation [27], expanding study populations beyond physical disabilities has been emphasised as a priority for participation-focused research [16, 18].

This scoping review is a key component of a needs assessment being undertaken by our research group. We have used the outcomes of this review to directly inform the development of an intervention that aims to improve participation outcomes in community leisure activities for children and youth with disabilities. To guide us in identifying literature relating to optimal experiences and environments in community settings that may need to be considered for intervention design, the original question of this scoping review was ‘what makes community programs work?’ Scoping review methods encourage the revision of the research question following searching and familiarisation with a broad range of literature. Subsequently, the purpose of this review was revisited following this and a clearly articulated scope of inquiry was determined. The purpose of this review was to examine the extent, range and nature of research that describes the elements contributing to meaningful participation experiences in community activities in children and youth with disabilities, with a view to summarise, synthesise and disseminate findings to inform future interventions and research methodologies. The specific goals of this review were to (a), employ the ICF-CY [28] as a framework to describe literature relating to meaningful participation in children and youth with disabilities; (b), identify the components of community programs/activities that contribute to meaningful participation experiences, and (c), describe the ‘essential elements’ that should be considered when designing and implementing programs and interventions to enhance community participation.

2.3 METHODS

A scoping review method was identified as the most appropriate approach to investigate the research question. Scoping reviews aim to map the literature on a particular topic or research area, and identify key concepts, gaps in the research, and types and sources of evidence to inform practice, policy making and research [29]. Both Daudt et al. [30] and Levac et al. [31] have provided recommendations to clarify and enhance the original six-stage methodological framework for scoping reviews that was proposed by Arksey and O’Malley [29]. The stages include (a) identifying the research question, (b) searching for relevant studies, (c) selecting studies, (d) charting the data, (e) collating, summarizing, and reporting the results, and (f) consulting with stakeholders to inform or validate study findings [29]. This review follows the original framework with the updated recommendations from Daudt et al. [30] and Levac et al.
[31], including the assessment of quality of the literature. Whilst quality assessment is typically uncharacteristic of scoping reviews, we considered it essential in meeting the overall objective of this review.

2.3.1 SEARCH STRATEGY

Scoping methods emphasise a wide literature search with minimal limits on search terms to enable breadth of coverage [29]. A literature search was conducted using the electronic databases Medline (1966), Embase (1947), PsycINFO (1920), ERIC (1992), SportDiscus (1830), CINAHL (1982), Scopus (2004) and Web of Science (2004), for publications from the databases earliest records until their most recent (December 2013). Reference lists of selected articles were also reviewed for novel studies. Key search terms were grouped into four concepts; (i), community, community program, community activity, recreation, leisure, adapted recreation, adapted physical activity, and therapeutic recreation; (ii), participation, social, inclusion, involve, engage; (iii), disability, disabled persons; and (iv), pediatric, child, adolescent, and youth. Search terms were truncated, exploded and adjusted with the assistance of a librarian to comply with each of the databases.

2.3.2 STUDY SELECTION

The scoping review process is iterative, requiring researchers to engage in a reflexive way, and where necessary, repeat steps to ensure a comprehensive approach [29]. Researchers are encouraged to define (and refine) the inclusion criteria post hoc, based on increasing familiarity with the literature [29]. Following multiple readings of titles and abstracts, and the revision of the search question, articles were included if they; (i) described the experience of children and/or youth participating in a community-based program or activity, (ii) included the perspectives of children and youth with any type of disability with an age range between 0-21 and/or their parents, and (iii) was published in English. Disability was defined as ‘long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders full and effective participation in society on an equal basis with others’ [32 Article 1]. The ICF-CY definitions of ‘community participation’ and ‘recreation and leisure’ were used to determine the inclusion of articles describing community programs and activities [28]. Studies were excluded if they focused on participation in school and/or work and volunteer activities, or the sample consisted of children and youth with a chronic disease (e.g. cancer, diabetes) as their primary diagnosis. Two reviewers independently assessed the relevance of selected articles.

2.3.3 CHARTING THE DATA
Data were extracted from articles into a charting framework containing descriptive entries and specific thematic information [29]. Each reference was allocated a unique reference number and organised by author, date of publication, country, characteristics of the study population, quality and level of evidence, type of community activity or program, and elements identified as contributing to meaningful participation experiences.

### 2.3.4 Assessment of Methodological Quality

Two authors independently evaluated the quality of each study, using the qualitative assessment tool developed by Kmet et al. [33]. The assessment tool consists of 10 questions, with guidelines for scoring quality and a scoring system. The calculated scores were used to classify the quality of each study as either very strong (90-100%), strong (70-89%), adequate (50-69%) and limited (<50%) [34]. In cases of disagreement, details were discussed until consensus was reached. The same two authors also determined the level of evidence of each study based on the guidelines developed by the Joanna Briggs Institute [35, 36].

### 2.3.5 Collating, Summarizing, and Reporting the Results

Descriptive statistics were performed to characterise the included studies and identify the extent of the research, and meta-ethnography [37] used to synthesise qualitative data. The inclusion of an assessment of the quality of evidence provided an understanding of the weight of the evidence in relation to the elements that should be considered when designing interventions or programs. The meta-ethnographical synthesis was based on the approach described by Noblit and Hare [37]. Initially, multiple readings of the studies were undertaken to gain an understanding of the concepts and interpretations unique to each study. Reciprocal translation analysis, analogous to constant comparison in primary qualitative research, was used to translate the findings of one paper into another by systematically comparing qualitative data from each study. Secondly, a refutational synthesis was undertaken to examine the similarities and differences in the findings of individual studies, and to develop a new, broader understanding of the elements contributing to meaningful participation experiences [37]. Together, translations and interpretations were used to generate a line-of-argument synthesis to answer the review question. Rather than simply aggregating the data, the line of argument synthesis re-conceptualised key themes to both synthesise and extend the findings of the individual component studies [37]. In doing so, recommendations from Dixon-Woods et al. [38] were followed to integrate the evidence from the review into a coherent theoretical framework. Elements were linked to corresponding ICF-CY chapter codes and presented within the associated component of the ICF-CY framework. This enabled a more insightful, formalised and generalisable way of understanding and explaining the elements contributing to meaningful participation experiences in children and youth with disabilities.
2.3.6 Consulting with Stakeholders

Our research team recognised the importance of involving consumers and the community in the research process, employing a steering group to guide all aspects of this review and the broader project it was designed to inform. Although described as an optional step [29], consultation with stakeholders occurred throughout the analysis and reporting of this review to validate findings and inform further stages of our research. Stakeholders included an adolescent with a disability, parents of children and adolescents disabilities, a disability policy advisor, clinicians working with children with disabilities in hospital and community settings, and representatives from non-government advocacy and support organisations in the community. Given that the outcomes of this review may be of particular interest to practitioners, community organisations and parents, we viewed consultation as an integral component of ensuring the richness of the research process and the translation of results.

2.4 Results

A total of 9544 references were identified, which was reduced to 7600 after the removal of duplicates. The article titles, abstracts and full text were reviewed, with 20 of the identified articles meeting the inclusion criteria (figure 2.1). The primary reasons for excluding articles were that; (i) the experience of a program, activity or intervention was presented as quantitative outcomes that were not reflective of the meaning of the experience (59%), and (ii) they examined participation in other settings (e.g. school) (41%).
2.4.1 STUDY DESIGNS AND LEVELS OF EVIDENCE

The 20 selected studies were published between 1999 and 2013, and all studies were qualitative in nature. One mixed-methods study was included [39], as the qualitative data met the review inclusion criteria and was reflective and explanatory of the quantitative results. Nine articles used semi-structured interviews to gather data [40-48], and eight used a combination of interview methods and at least one other qualitative method (observation, photo voice, journals, mosaic methods and/or field notes) [49-56]. Two articles presented findings based on data from qualitative surveys [39, 57], and one described their methods as ‘key informant activities’, using individual computer-based activities for adolescents and discussion groups for parents [58]. Table 2.1 summarises the descriptive characteristics of the studies.

**Figure 2.1** Flowchart of study selection process
Table 2.1 Descriptive characteristics of studies

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Description of study population</th>
<th>Qualitative methods</th>
<th>Perspective</th>
<th>Quality</th>
<th>Community activity or program</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson 2009 USA</td>
<td>13 girls (10-18 years) with physical disabilities (CP, lower limb amputation, non-specified limited mobility, osteogenesis imperfecta and spina bifida)</td>
<td>Semi-structured interviews</td>
<td>Child Parent Other</td>
<td>Strong quality (17/20)</td>
<td>Blazesports America (basketball, swimming, track &amp; field)</td>
<td>S</td>
</tr>
<tr>
<td>Anderson, Bedini &amp; Moreland 2005 USA</td>
<td>14 girls (10-16 years) with physical disabilities (CP, non-specified limited mobility, osteogenesis imperfecta and spina bifida)</td>
<td>Semi-structured interviews</td>
<td>Child Parent Other</td>
<td>Very strong quality (18/20)</td>
<td>Formal and informal active recreation activities</td>
<td>S</td>
</tr>
<tr>
<td>Anderson, Wozencroft &amp; Bedini 2008 USA</td>
<td>22 girls (10-18 years) with physical disabilities (ABI, CP, lower limb amputation, non-specified limited mobility, osteogenesis imperfecta and spina bifida)</td>
<td>Semi-structured interviews</td>
<td>Child Parent Other</td>
<td>Very strong quality (19/20)</td>
<td>Blazesports America (basketball, swimming, track &amp; field)</td>
<td>S</td>
</tr>
<tr>
<td>Bedini &amp; Anderson 2005 USA</td>
<td>11 girls (10-16 years) with physical disabilities (ABI, CP, non-specified limited mobility, osteogenesis imperfecta and spina bifida)</td>
<td>Semi-structured interviews</td>
<td>Child Parent Other</td>
<td>Very strong quality (19/20)</td>
<td>Formal and informal physical recreation activities</td>
<td>S</td>
</tr>
<tr>
<td>Author(s) &amp; Year</td>
<td>Population</td>
<td>Methodology</td>
<td>Quality</td>
<td>Program/Activity</td>
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<tr>
<td>Bedini &amp; Thomas 2012</td>
<td>Children with physical disabilities; parents of children with physical disabilities</td>
<td>Descriptive article; Qualitative survey</td>
<td>Limited quality (8/20). No description of participants, sampling, data collection or analysis.</td>
<td>Adapted sports program</td>
<td></td>
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<tr>
<td>Burke 2012</td>
<td>35 children (6-10 years) with intellectual and motor impairments</td>
<td>Observation, photo-voice, focus group interviews</td>
<td>Adequate quality (12/20). Only partial description of participant sampling, data collection and analysis.</td>
<td>Playground</td>
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</tr>
<tr>
<td>Castenda &amp; Sherrill 1999</td>
<td>16 children (7-16 years; 10 boys, 6 girls) with a range of diagnoses (autism, CP, Downs syndrome, intellectual disability, muscular dystrophy, TBI); 15 mothers (28-56 years); 13 fathers (31-53 years); 9 brothers (5-18 years); 8 sisters (0.25-15 years); 2 'other' members of family units (33-35 years old)</td>
<td>Semi-structured interviews, observation</td>
<td>Very strong quality (19/20)</td>
<td>Challenger Baseball League</td>
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<tr>
<td>Devine &amp; O'Brien 2007</td>
<td>4 children (12-16 years; 1 boy 3 girls) with a range of diagnoses (Aspergers, CP, spinal muscular atrophy)</td>
<td>Semi-structured interviews</td>
<td>Very strong quality (19/20)</td>
<td>Summer camp</td>
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<tr>
<td>Study</td>
<td>Sample Description</td>
<td>Data Collection Methods</td>
<td>Quality Rating</td>
<td>Programme/Service</td>
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<tr>
<td>Goodwin et al. 2004 Canada</td>
<td>5 children (6-14 years; 1 boy, 4 girls) with spina bifida; parents</td>
<td>Semi-structured interviews, focus groups, journals, visual documentation, field notes</td>
<td>Strong quality (16/20)</td>
<td>Wheelchair dancing</td>
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<tr>
<td>Goodwin &amp; Staples 2005 Canada</td>
<td>9 youth (14-19 years; 5 boys, 4 girls) with a range of diagnoses (auditory impairment, autism, CP, mobility impairment, visual impairment); Mothers of youth with disabilities</td>
<td>Semi-structured interviews, photo-voice, field notes</td>
<td>Very strong quality (18/20)</td>
<td>Sports and recreation summer camp</td>
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<tr>
<td>Goodwin et al. 2011 USA</td>
<td>13 children (9-15 years; 6 boys, 7 girls) with vision impairments</td>
<td>Semi-structured focus group interviews, field notes</td>
<td>Very strong quality (19/20)</td>
<td>Sports and recreation summer camp</td>
<td></td>
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<tr>
<td>Groff &amp; Douglas 2001 USA</td>
<td>11 youth (15-21 years; 7 boys, 4 girls) with physical disabilities (CP, oxigenesis imperfectus, spina bifida, TBI)</td>
<td>Semi-structured interviews</td>
<td>Very strong quality (19/20)</td>
<td>Adapted sports program</td>
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<tr>
<td>Heah et al. 2007 Canada</td>
<td>8 children (6-15 years; 5 boys, 3 girls) with a range of diagnoses (autism, CP, developmental delay, epilepsy, spina bifida); 8 parents (1 father, 7 mothers)</td>
<td>Semi-structured interviews</td>
<td>Very strong quality (18/20)</td>
<td>Formal and informal recreation activities</td>
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<tr>
<td>Study</td>
<td>Participants (Age; Gender)</td>
<td>Methodologies</td>
<td>Quality (Score)</td>
<td>Program</td>
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<tr>
<td>Kristen et al.</td>
<td>20 children (9-15 years; 13 boys, 7 girls) with physical disabilities (CP, spina bifida, muscular disease, deficiency in attention, motor control and perception (DAMP), rheumatoid arthritis, heart disease)</td>
<td>Semi-structured interviews</td>
<td>Very strong quality (18/20)</td>
<td>Adapted sports program</td>
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<tr>
<td>Kristen et al.</td>
<td>20 parents (30-51 years; 11 mothers, 9 fathers) of children with physical disabilities</td>
<td>Semi-structured interviews</td>
<td>Very strong quality (19/20)</td>
<td>Adapted sports program</td>
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<tr>
<td>Lyons et al.</td>
<td>42 parents of children with disabilities</td>
<td>Qualitative survey</td>
<td>Good quality (15/20). Limited description of data analysis; no verification or reflexivity procedures.</td>
<td>The Miracle League (Adapted baseball league)</td>
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</tr>
<tr>
<td>Parkyn &amp; Coveney 2011</td>
<td>12 boys (14-17) with muscular dystrophy; 12 mothers</td>
<td>Key-informant group activities (boys) and discussions (parents); online forum</td>
<td>Very strong quality (18/20)</td>
<td>Recreation activity group (MD Mafia)</td>
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<tr>
<td>Pickering et al.</td>
<td>25 children (2-17 years; 12 boys, 13 girls) with CP (GMFCS Level I-IV)</td>
<td>Structured interviews, mosaic methods</td>
<td>Strong quality (16/20)</td>
<td>Adapted Cycling program</td>
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<tr>
<td>Study</td>
<td>Sample Description</td>
<td>Methodology</td>
<td>Quality Rating</td>
<td>Activity Type</td>
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<tr>
<td>Spencer-Cavaliere &amp; Watkinson 2010 Canada</td>
<td>11 children (8-12 years; 9 boys, 2 girls) with a range of diagnoses (CP, fine and gross motor delays, DCD, muscular dystrophy, nemaline myopathy, brachial plexus injury, severe asthma)</td>
<td>Semi-structured interviews, field notes</td>
<td>Very strong quality (20/20)</td>
<td>Formal and informal physical activity</td>
<td></td>
<td></td>
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<tr>
<td>Wright et al. 2004 USA</td>
<td>5 boys (4-11 years) with spastic diplegia CP; parents and therapists</td>
<td>Structured interviews, observation, field notes</td>
<td>Very strong quality (18/20)</td>
<td>Adapted martial arts program</td>
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</tbody>
</table>

As the articles included in this review were qualitative, all studies were of level 3 according to the Joanna Briggs Institute hierarchy of scientific evidence for meaningfulness [35]. When article quality was assessed, seventeen of the twenty studies had very strong (14 90-100%) or strong (380-89%) quality scores. One article scored below 50%, due to the very limited information regarding data collection and analysis procedures [57]. However, the article answered the research question and provided direct quotes from parents and children regarding their participation experiences in the sports program, so it was therefore included.

2.4.2 Participant characteristics

The majority of studies examined a heterogenous sample of disability diagnoses (n=15), with authors referring to their sample as ‘children with disabilities’ (n=6), or children with physical disabilities (n=9). ‘Physical disabilities’ referred to conditions which restricted mobility due to neurological-based and musculoskeletal disorders. ‘Children with disabilities’ referred to a range of intellectual, developmental, sensory and motor impairments, including physical disability. One study detailed disability as ‘intellectual and motor impairments’, and provided no further information regarding specific diagnoses [49].

Studies that had a homogenous sample group examined children with Cerebral Palsy (n=2), muscular dystrophy, spina bifida, and vision impairment. One study [46] also included data from children without a disability. This study was included, as data from children with and without disabilities was presented separately in the results. The mean age range of the children and youth in the studies fell between 8.9-15.6 years. Sixteen studies reported the gender of children, of which 57% of the total participants were girls, and 43% boys.

2.4.3 Setting

Table 2.1 presents details of the setting of all studies. Articles were categorised according to their organisational structure; formal or informal, and segregated or inclusive (see table 2.2 for definitions of terms). The majority of recreation and leisure activities were formal community programs [39, 40, 42, 44, 46–48, 50–53, 55–58]. Of these, only one was conducted in an inclusive program setting [46]. The recreation and leisure programs and activities described in the studies were overwhelmingly physical in nature. Eighteen of the 20 articles examined participation in sport, active recreation and/or physical activities, including studies conducted within a summer camp setting [39, 40, 42–57].
### Table 2.2 Definition of terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>Formal activity</td>
<td>A structured community program; an activity that has structure, rules and organisation, involves leaders, and generally requires pre-planning [4]</td>
</tr>
<tr>
<td>Informal activity</td>
<td>No specific personal or structural parameters for activities, typically spontaneous, and occur with less planning [4]. E.g. playing on a playground, kicking a ball in the park.</td>
</tr>
<tr>
<td>Segregated</td>
<td>The activity or program is specifically for children with disabilities.</td>
</tr>
<tr>
<td>Inclusive</td>
<td>The activity or program includes both children with and without disabilities.</td>
</tr>
</tbody>
</table>

#### 2.4.5 Meta-ethnographical analysis

Reciprocal analysis identified elements contributing to meaningful participation experiences in recreation and leisure activities in children with disabilities. From the analysis of codes, pattern regularities and relationships across studies, themes were developed. These themes are presented within the domains of the ICF-CY [28]. The differences between type of activity (formal/informal), environment (segregated/inclusive), age and gender relative to elements were considered throughout the development of themes. Although no studies seemingly refuted each other within each of these considerations, interpretations of the role the environment in identity development differed between some authors.

Ten themes, presented as essential elements, inductively constructed a new whole from the elements identified in the reviewed studies. Articles contributing to each of these themes can be seen in table 2.3. The ten elements contributing to meaningful participation experiences are described below.
<table>
<thead>
<tr>
<th>Author</th>
<th>Themes</th>
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<tbody>
<tr>
<td></td>
<td>Authentic friendships</td>
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<tr>
<td>[42] Anderson</td>
<td>•</td>
</tr>
<tr>
<td>[44] Anderson et al. 2005</td>
<td>•</td>
</tr>
<tr>
<td>[43] Anderson et al. 2008</td>
<td>•</td>
</tr>
<tr>
<td>[45] Bedini and Anderson</td>
<td>•</td>
</tr>
<tr>
<td>[57] Bedini and Thomas</td>
<td>•</td>
</tr>
<tr>
<td>[49] Burke</td>
<td>•</td>
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<tr>
<td>[50] Castenda and Sherrill</td>
<td>•</td>
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<tr>
<td>[46] Devine &amp; O’Brien</td>
<td>•</td>
</tr>
<tr>
<td>[51] Goodwin et al. 2004</td>
<td>•</td>
</tr>
<tr>
<td>[56] Goodwin and Staples</td>
<td>•</td>
</tr>
<tr>
<td>[52] Goodwin et al. 2011</td>
<td>•</td>
</tr>
<tr>
<td>[47] Groff and Kleiber</td>
<td>•</td>
</tr>
<tr>
<td>[41] Heah et al.</td>
<td>•</td>
</tr>
<tr>
<td>[48] Kristen et al. 2002</td>
<td>•</td>
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<tr>
<td>[40] Kristen et al. 2003</td>
<td>•</td>
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<tr>
<td>[39] Lyons et al.</td>
<td>•</td>
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<tr>
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<td>Authors</td>
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<tr>
<td>58</td>
<td>Parkyn and Coveney</td>
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2.4.5.1 Person-based Elements

Having Fun

Having fun was identified by nineteen articles included in this review as a crucial component of meaningful participation experiences:

"I dance because it is fun. I feel very happy when I dance." [51, p.237].

Children participated in activities to feel happy, to experience the joy of movement and the enjoyment associated with being with others. Ultimately, participation in these activities was associated with the inherent enjoyment associated with them:

"I felt really good about myself" [44, p.197] and, "When I’m having fun, I don’t really like to stop." [44, p.41].

Friends and socialisation were recognised as significant contributors to having fun during activities [39, 42, 44, 47, 54, 56, 58]. Modification to rules and equipment were identified by parents in two studies as an important contributor to the enjoyment associated with participation in formal sports programs [50, 57].

Experiencing Success

Activities where children could experience success were consistently described as meaningful [39, 41, 42, 44, 50, 57]. Successful experiences influenced a child’s activity choices, persistence and overall enjoyment of an activity:

"...it used to be like...me saying ‘yeah, I know you’re going to beat me ‘cause you’re better’ but now it’s like ‘try to catch me.’" [42, p.441].

Participation in formal community activities allowed children to recognise and understand their capabilities. These activities also encouraged children and youth to consider future aspirations and set long term goals [42, 44, 53]. Children described transferring the skills they gained through participating in community activities to other aspects of their lives:

"I know that if I can play basketball and all those other sports then I can probably do other things" [47, p.324].

The perceptions of others regarding their participation in activities, and having the opportunity to prove their competence to their peers was also highlighted as meaningful and motivating to children:
“They think it’s amazing that I play wheelchair basketball.” [43, p.92].

Being proud was an effect of the mastery experiences of children in community activities. A sense of pride was experienced following observations of competence (themselves and others), experiences of success and from formal recognitions. As described by Groff and Kleiber [47], ‘Taylor indicated that receiving the coaches award provided him with a sense of pride because, “It shows that people know that I am trying to work hard” ’ [47, p.325]. When Mitch was presented an award for best defence he said, "I could not believe it…My face was so happy and I was just laughing” ’ [47, p.325].

BELONGING

A sense of belonging was essential in creating meaningful and enjoyable participation experiences for children and adolescents. In the context of recreation and leisure activities for children with disabilities, belonging had several dimensions. Such activities provided an environment that children and adolescents could actively join, feel a sense of connectedness among others, and remove them from the sense of isolation they experienced in other aspects of their lives. For many children, belonging was related to the sense of acceptance children experienced in these activities:

“Cause I know my friends see me for who I am on the inside, not on the outside only” [46, p.217].

The social connectedness developed through shared experiences was salient to all studies. Its contribution to a child’s sense of belonging was reflected in the shared experience of an activity:

“You kind of get on a whole new level when you compete because you have people who understand you better” [42, p.442].

In segregated activities, this was reflected through the shared experience of disability:

“It was an experience I will never forget because we connected so well. Everyone understood and you didn’t have to worry about people judging you” [56, p.168].

Belonging to the community was important to both children and their families in creating meaningful experiences. Being involved in one activity in the community connected children to a wider group of people [42, 50, 51, 53] and connected children and their families to more organisations within the community [41, 53].

“He feels like he's a part of society. He's just not a spectator. He's actually out there being a part of it, which is something he's never had the opportunity to do before.” [50, p.382]
In this sense, participation in community activities also acted as a normalising experience for children and their families. This was evident in both segregated and inclusive activities in the community:

“The opportunity that [Miracle League] gives to each child with a disability to feel like a regular, non-disabled child, if only for an hour” [39, p.45].

“I feel better doing things like regular people.” [43, p.91].

Belonging was also described as being a valued participant [46, 49, 50, 54], and contributed significantly to the meaning of the activity. Spencer-Cavaliere and Watkinson [54] described that feeling like a legitimate participant is dependent on the behaviours of others, and that this could enhance or challenge a child’s sense of belonging and value as a participant [54]. This highlighted the differences between being included and feeling included, emphasising the need for inclusion to be understood as a subjective experience of the individual:

“When you get picked on a team and you’re not always picked last” [54, p.285].

While many factors contributed a sense of belonging, it was considered an integral component of meaningful participation experiences in both segregated and inclusive activities.

EXPERIENCING FREEDOM

This theme represents the sense of freedom children and youth experienced whilst participating in community recreation activities. Freedom encompasses the key concepts presented by the studies relating to freedom from their disability and from constraints, the freedom to use their bodies, to express themselves, and experience the freedom of choice. Most frequently, community activities provided children an opportunity to be free from the constraints of their disability:

“Sometimes I just like to forget all about my disability and just have fun” [43, p.91].

Recreation activities also provided a setting for the children to be independent, free from the overprotectiveness they experience from their family:

“So I thought this is my opportunity to be away from Mom and Dad and most of my friends. I knew mom wasn’t going to come running; she can’t just drive up. It was neat” [56, p.169].

Activities in which children could freely express themselves held significant meaning. Children felt free to express emotion:
“It is really a socially-acceptable way for a person in a wheelchair, or even on crutches, to express anger” [47, p.325].

Similarly, children felt they could express their individuality. This was meaningful to parents to see others looking past the disability and to the child themselves:

‘The parents were grateful that they did not have to remind the instructors of the program that there was “a little person inside there”’ [51, p.236].

Experiencing freedom of choice was important for some children. Not only in terms of choosing the activity, but for choices made during activities. A boy with Asperger’s explained that he liked that his group gave him choices [46], and Wright et al. [55] demonstrated the impact of a karate program on the desire of children to participate in making group decisions. Ultimately, the freedom these children and youth experienced during activities was synonymous with opportunities where they felt they could openly be themselves.

**HAVING AN IDENTITY**

Over half of the studies described the opportunity to explore and develop an identity as integral to meaningful participation experiences in recreation and leisure activities for children and adolescents [40, 42, 43, 47, 48, 50–52, 55, 56, 58]. This was particularly evident in participation in formal sports programs, environments which support the development of athletic identity from being a part of a team or club. As described by Anderson [42], ‘Many of the girls see the desire to be a successful athlete as a core component of who they are’ [42, p.441].

The importance of identity was also reported by Parkyn and Coveney [58], in boys with muscular dystrophy who were part of a social group. They summarised that ‘the boys shared a clear view of the group identity. They adopted the name ‘MD Mafia’ and this has created the group image as ‘tough’, ‘scary’ and masculine. MD Mafia is for “boys only”’ [58, p.84].

Furthermore, the role of other children in identity development was considered crucial to children and youth. Groff and Kleiber explained that ‘social interactions with other individuals with disabilities expanded the reference groups these youth used as a source of information during the process of identity formation. In addition, feeling a sense of connectedness with others during adapted sport allowed most (but not all) of these adolescents an opportunity to feel as if they could truly be themselves’ [47, p.328].
In some instances, the identities children developed through their involvement in community activities also assisted in their inclusion in other environments. Anderson [42] described ‘Janie, a 10-year-old with spina bifida who plays basketball, most strongly identified the role that her identity as an athlete had played in her entrance into both the world of sport as well as the social world of her school…Her participation in sport had helped her identify a socially acceptable, and revered, identity, that of athlete’ [42, p.422]. Furthermore, some authors explored the idea that identity development within formal recreation contexts influenced identity formation in other areas of life [42, 47, 56].

Recreation and leisure activities in the community were described as environments that facilitated identity development. While some authors argued for more inclusive formal community programs [42, 45], others emphasised that it was the uniqueness of segregated programs that facilitated this [47, 51, 56]. Groff and Kleiber [47] argued that the potential for recreation activities to influence disability identity development is irrelevant if the opportunities to interact with others with disabilities are absent or far removed [47]. Goodwin and Staples [56] shared a similar perspective, describing participants as articulating their identity as youth with disabilities by connecting with a larger disability community [56]. The participants indicated that connecting with others with disabilities helped them to understand themselves better [56]. Goodwin et al. [51] also supported this, describing that affiliations with others who share common lived body experiences created a place of safety and comfort where one’s sense of self is not threatened [51]. Studies that included perspectives from children participating in informal activities made no reference to these environments facilitating identity formation.

Age and gender were described as influencing identity and participation in two studies. Having children who were the same age and gender were considered crucial to the success of the social boys group [58], whereas girls participating in disability sports referred to male teammates as being instrumental to their own participation [43].

2.4.5.2 Environment-focused Elements

Authentic Friendships

Having friends was the most prevalent theme that emerged from the meta-ethnographic data. It was identified in every study as an essential component of meaningful experiences. Across all studies, it was a child’s peers (or lack of) that appeared to be the most important feature of a child’s perceptions of inclusion or exclusion:
“It’s nice to have friends and not to feel left out and someone you can actually trust...because friends make you feel comfortable with yourself like because there’s always someone there for you” [54, p. 285].

To children and youth with disabilities, friendships represented an uncontrived acceptance from others. This was a salient feature of both having fun and fostering a sense of belonging. Friends also provided a ‘positive peer pressure’ that motivated children to take on challenges they may not have otherwise sought.

“I think it helped him to take that step forward. He tried things because his peers were there that he would not have done otherwise” [56, p.170].

The significance of friendships was an overarching theme of all studies included in this review. Parents and children alike attributed meaningful peer relationships and social interactions as integral in positive activity experiences.

**THE OPPORTUNITY TO PARTICIPATE**

While clearly a precursor to participation, the opportunity to participate was considered an integral element across many studies. Just having the chance to participate held significant meaning to children, adolescents and their families:

“I was just glad to see that she could finally get on a team and play a game. That’s what I was excited about. Just to have an opportunity” [50, p. 382].

The importance of the opportunity to participate was also emphasised when children expressed what their life would be like without these activities:

“I wouldn't have as much to do...I would be more lazy like I was and I wouldn't be as hard of a worker” [47, p.326],

and again when the lack of opportunities became apparent:

“Wheelchair fencing was one of the new sports I tried. I liked it a lot. I would have liked to have tried wheelchair fencing when I got home, but unfortunately, we have no sports organizations or teams for physically disabled kids. Too bad” [56, p.172].

Having suitable, accessible programs that offer children with disabilities the opportunity to participate was of significant value children and their families:
“I finally got my dream. All my life I wanted to be a ballet dancer, and now I am one, yahoo!” [51, p.237].

ROLE MODELS

While only half of the included studies referred to role models, those that did identified these as a critical factor contributing to their participation. Role models ranged from high profile athletes, older participants within the sporting club, coaches and instructors, family members and peers. Role models played a variety of roles, motivating children to engage in these activities initially, providing challenges to explore their limits, initiate goal development, provide competition, social and emotional support, and mentoring through similar life situations.

“Role models are very important…you see them doing it, and you think to yourself, ‘well, I can do this’” [42, p.441].

For those children and youth that recognised themselves as role models for others, the fulfilment this provided also contributed to the meaning of the activity:

“They look up to me, it’s actually kind of nice” [51, p.241].

FAMILY SUPPORT

Generally, meaningful participation in activities in the community was influenced by a child’s family. The central support roles that parents played in their child’s experiences was described by both children,

“Oh they love it. They come out for competitions all the time, you know. It’s not just one parent coming with me its a, you load up the whole van, my whole family comes. So it's like a family thing” [44, p.195],

and their parents:

“We experience emotional highs that we don’t get to experience anywhere else because we can't” [50, p.384].

The reciprocity of meaningful participation between children and their families was emphasised in some studies; participating in organised activity was considered as fun and exciting for everyone involved:

‘Husain persuaded his mother to ride a bike for the first time. They had come from an African country where this opportunity had never been available. Emily
encouraged her grandmother to ride a bike and they all went off on a ‘picnic and explored in search of the Gruffalo’ [53, p.1042].

There were some mixed responses from children regarding the impact of their families support. Encouragement was generally seen as positive, but others felt pressured by their family’s values:

“My mom wants me to get like really into it and I…I wanna be good at a sport, but I don’t want to go pro at a sport…I wanna have fun” [44, p.198].

2.4.5.3 Activity-related elements

Learning

Learning experiences were meaningful to children and adolescents during their participation in community activities. ‘Learning’ referred not only to skill exposure and acquisition, but also to discoveries the children made about themselves and others during activities. Learning new skills held significant meaning to children and adolescents in the activities. This was particularly evident in camp experiences [46, 52, 56]:

“Like I get to do things that I don’t normally do, some really different things” [46, p.217]

Additionally, being able to take on new challenges in a ‘safe’ environment was important to children. Of interest, this was only identified in segregated activities in the community [51, 52, 56, 58]

“I don’t know how to explain it, it’s like I don’t want to do things because if you do something silly or if my wheels get stuck they all laugh at me. But here, because they are in a wheelchair too, they understand that ‘oops, it’s okay, just get on with it’” [51, p.236].

Adaptations and modifications to rules and equipment was also considered important in facilitating these learning experiences, allowing children to simultaneously learn and have fun [50]. It was also important to children that coaches, instructors and supervising adults acknowledge their existing skills:

“I think that we should be able to…really do something all on our own. We should be able to show our coach that we can actually do it so that they have a basis to you know whether they tell us that we can do or not” [52, p.49].
Learning about their own abilities, and subsequently exploring their limitations was a meaningful part of children’s participation. One child explained:

“I learned that my limitations are pretty high. I can do almost pretty much anything. I also learned that it’s different for everyone. No matter what your ability is, you can still participate in different activities” [56, p. 171].

Discovering the abilities of others was often an unexpected motivational tool for children and adolescents:

“It was inspirational. I saw other youth that have worse disabilities than me and I saw how they did the activities” [56, p. 171].

2.4.6 Consultation with Stakeholders:

Although optional, our research team considered the sixth stage of scoping review methodology to be a necessary component of this review. While the research team was uncertain whether or not to include ‘the opportunity to participate’ as a major theme, the feedback from the steering group was overwhelmingly in support of its inclusion. Adolescents with a disability, parents and clinicians emphasised that not having opportunities to participate was a major barrier in their communities. The lack of available participation options meant that when they were presented with these opportunities, they were highly valued by children and parents. Subsequently, this contributed significantly to the overall meaning of the experience for the child and their family.

On review of all themes, the steering group explored the idea that these elements can and do apply across settings, and the lifespan. When asked if these themes accurately represent participation experiences in recreation and leisure activities, an adolescent boy with an acquired brain injury commented:

“I think it’s pretty accurate because it relates to this topic that all human beings have this search for meaning in life”.

Thematic findings of the review are depicted in Figure 2.2 and are discussed below.
This scoping review demonstrates the utility of the ICF-CY as a framework to synthesise literature relating to meaningful participation in children and youth with disabilities. Understanding the elements that create meaningful participation experiences within the ICF-CY framework has highlighted the significant contribution of contextual factors in community leisure participation. Themes relating to supportive relationships (authentic friendships, family support and role models) and services, systems and policies (the opportunity to participate) identify specific aspects of the environment that may need to be considered by health professionals to facilitate community leisure participation in children and youth with disabilities. This review also demonstrates the role of personal factors, characteristics that are intrinsic to the child or youth [28], in motivating and engaging children and youth with disabilities within community participatory contexts (see figure 2.2). The themes were interrelated, in that aspects of one were pertinent to the others. For example, having friends was a crucial component of having fun, and a sense of belonging was associated with identity development. This is evident in figure 2.2, emphasising that these elements are not mutually exclusive, but rather interdependent of each other.
This review reveals the substantial contribution that meaningful interactions with others have in creating positive and engaging experiences. Six of the 10 elements refer to feelings, relationships and experiences that were facilitated by the presence of others (authentic friendships, belonging, having fun, role models, having an identity, and family support). Deci and Ryan [59] proposed that activities and goals are pursued because individuals are motivated to fulfil needs for autonomy, relatedness and competence. Results from this review described that meaningful participation experiences embody elements that are characteristic of autonomous pursuits (experiencing freedom) and perceptions of competence (learning, experiencing success), but also highlight the potentially significant role of relatedness in children with disabilities. Interestingly, relatedness has been identified as the most important need among adults with disabilities during and following their participation in an adapted physical activity program [60]. Similar to outcomes of this review, this was attributed to possibilities created by the program environment to share experiences with others with disabilities in activities, and be valued by peers [60]. In out-of-school activities for children with disabilities, greater social acceptance has been associated with greater enjoyment of social and skill-based activities [61]. Participating in team sports has also been shown to mediate perceptions of loneliness for boys with developmental coordination disorder [62]. The concept of relatedness may therefore be particularly important to consider in the development of participation interventions for children with disabilities. Group-based designs may facilitate the development of social networks similar to those embodied in community-based programs, and encourage ongoing participation in their chosen leisure pursuits post-intervention.

Self-determination theory (SDT) is increasingly being applied to understand motivation and engagement in children with disabilities [26, 27, 63]. Most recently, a systematic evidence synthesis by Powrie et al. [27] concluded that the findings relating to the meaning of leisure for children and young people with physical disabilities resonated most strongly with SDT. The four themes core to the meaning of leisure (fun, freedom, fulfilment, and friendship [27]) were also identified as themes in this review (having fun, experiencing freedom, learning/experiencing success, authentic friendships/belonging). Importantly, our review not only supports but also extends the findings of Powrie et al [27]. This review was not limited to physical disability, and thus captured a wider cohort of articles and diagnoses within its search parameters; articles describing the meaning of experience for children with sensory impairments, intellectual disabilities, autism spectrum disorders, epilepsy and developmental delay also contributed to our data set. Unique to this review, developing an identity, having role models, family support, and the opportunity to participate, were identified as essential elements contributing to the meaning of experience in community leisure activities for children, independent of disability type. This has implications for intervention design; as well as the
centrality of friendship and social connectedness [27], relationships with mentors, family and services in the wider community may need to be considered as key ingredients to attaining community participation goals for children and youth with disabilities.

This review adds further support to the notion of ‘activity settings’ [19] to conceptualise the participation environments of children with disabilities. Activity settings reflect both the role of the environment in participation and the meaning attached to places, people and activities [64]. Consistent with literature outlining the essential elements of community programs for typically developing youth [65, 66], this review found that children with disabilities engage with environments in which they experience a sense of belonging and success, can develop authentic relationships among peers, and learn new skills that can be transferred into other contexts. While the term ‘environment’ most often refers to physical, socio-cultural, or political factors affecting the individual, this does not necessarily provide a clear understanding of the mechanisms by which specific environmental qualities lead to optimal participation experiences. This was evident in this review, which identified the role of segregated recreation environments in facilitating identity formation. The views of children and youth indicated that involvement in an activity designed specifically for individuals with disabilities allowed them to identify and confirm aspects of their identity. Such environments were thought to create a context that allowed their identities to unfold at both the individual and group level. Given that the principle function of identity formation is fostering the experience of relatedness [67, 68], providing environments where children and youth with disabilities can connect with other children and youth with disabilities may provide an opportunity to both interact with others and reflect on the attributes of themselves. Applying the concept of ‘activity setting’ in future research may help to narrow the scope of ‘environment’, enabling us to consider how qualities of settings present the opportunity for a variety of experiences [19].

Just having the opportunity to participate was emphasised extensively throughout many of the studies included in this review, and an element that was further reinforced during our analysis in our consultation with stakeholders. While the research base describing barriers and facilitators to participation in community activities is well established, the outcomes of this review adds further emphasis to the need to take action. This may mean working across contexts; in order to ensure long-term changes in participation outcomes following targeted interventions, we need to ensure the availability and accessibility of services in our local communities. While this review may assist us in our ability to design interventions that create positive participatory experiences, it is equally important to ensure the maintenance and sustainability of these environments following the conclusion of these.
2.5.1 Clinical implications

This review provides a comprehensive overview of the elements that may be required for changing and maintaining outcomes in recreation and leisure activities in children and youth with disabilities. It represents an aggregate and novel approach to understanding the motivating and engaging factors for community participation in children and youth with disabilities. These elements should be considered as core components of interventions being developed to improve participation outcomes in community-based leisure activities.

Knowledge concerning the elements essential for positive participation experiences and, in turn, for health, development and well-being, has broad significance. One of the most frequently identified goals of children and young people at the outset of therapy is to enhance skills they need to engage more fully in a valued leisure activity [69]. Being aware of these elements may assist researchers and clinicians in the design of interventions to improve participation outcomes, and may increase their likelihood of success. Similarly, this review may also be relevant for parents, teachers and community activity organisations, as motivation is a critical variable in producing maintained change [70].

While the ICF-CY has proven to be an effective model for use by researchers and therapists alike, this research adds to the growing call to encompass subjective aspects of measurement that relate to the meaning and importance of participating in an activity [10, 11]. Outcomes of this review may guide clinicians in their choice of variables to include and observe during interventions. The fulfilment of personal goals and societal roles that are of importance to the child and their family may provide the highest quality information relating to meaningful outcomes [71]. With the exception of the SEAS [23], participation measures typically focus on what children/youth are doing in life situations, with whom, and the frequency and intensity of their participation. Obtaining and valuing the perspectives and preferences of children and youth is essential if we wish to make meaningful, long term changes to their health and quality of life. This review highlights the value of including and understanding characteristics intrinsic to the child that impact upon their participation experiences within our measurement.

Importantly, this review demonstrates the limited negative impact impairment has on a child’s participation experience. While research outlines this as a barrier to a child’s participation, children’s perspectives from this review associated their disability as a positive contributor to parts of their experiences. Activities where children were of similar functional ability or diagnoses provided environments in which they could learn from each other and realise their potential, connect with
others through a shared experience and feel like they belong. Moving away from inclusive service delivery may not be a step backward in terms of equity of access and social justice [72], but rather an environmental factor clinicians and service providers need to consider on an individual client basis.

2.5.2 Research gaps and future directions:

This scoping review reveals several gaps in the literature. The majority of studies included in this review described experiences of participating in formal and segregated environments. We currently know little about the participation experiences of children and youth with disabilities in informal and inclusive settings outside of school. Such activities have previously been identified by youth as being important to their quality of life [73]. Longitudinal qualitative inquiry may assist our understanding in meaningful leisure participation as children and youth transition through life stages.

The physical nature of the activities included in this review may not necessarily reflect the actual activity choices of children and youth with disabilities. Research has shown that children with disabilities participate in fewer active than non-active out-of-school activities [4, 16]. As the majority of articles in this review were of experiences in active recreation, applicability of these elements to pursuits such as drama, music, and informal social activities is limited. This highlights a significant gap in the literature, whereby other types of meaningful activities have received little attention. Findings from this review may be particularly useful for researchers and health professionals attempting to engage children and youth with disabilities in physical activity.

Additional gaps identified in this review were highlighted in the country of location the included studies were conducted; our understanding of participation experiences is limited to those of western societies. It is imperative that children and youth from other global localities and cultural backgrounds are asked for their perspectives regarding meaningful participation experiences in their communities, as they may have different needs and values regarding activities, relationships and environments. Research methods such as participatory action research [74], and measurement approaches such as yarning [75], are culturally safe processes that may be useful in obtaining these perspectives.

This review fills an important gap in the literature. There is limited synthesised evidence that assists in our understanding of ‘meaningful participation’ for children and youth with disabilities [27], and further examination of these contributing elements is needed. Identifying the underlying mechanisms of the relationships between elements may be required to fully understand the influence each of these ten elements have on each other, and on creating positive participatory experiences. As the application
of SDT to the participation of children with disabilities is evolving [27, 63, 76], the potential importance of relatedness within recreation and leisure settings prompts the need for further research into identifying optimal conditions for facilitating relational processes. Developing and testing interventions that incorporate these elements to facilitate meaningful leisure experiences for children and youth with disabilities is forthcoming.

2.5.3 LIMITATIONS

There are some limitations associated with this review. As is typical of all qualitative research, the generalisability of these findings is limited. However, similarities in findings between this review and Powrie et al. [27] may add strength to the emerging literature that qualitative synthesis is a rigorous methodology for enhancing knowledge [27, 77, 78]. The inclusion of the assessment of quality of the literature further enhances the generalisability of these results, given the strong methodological quality of most of the articles. This did present some difficulties regarding the inclusion of studies of minimal quality; whilst strong research quality is favoured for dissemination and translation of results, a scoping review is primarily a mapping process, reviewing a range of evidence in order to convey the breadth and depth of a field [31]. Given these articles still contained data that contributed to our understanding of children’s and youth’s participation experiences, we chose to include all eligible studies. This may be a dilemma encountered by others that attempt to incorporate quality assessment within scoping studies.

A strength of our review was involving consumers and the community within the synthesis of findings. The steering group was invaluable in assisting in the generation of themes, development of the model and validating outcomes against their lived experiences. The contributions of a steering group in the analysis and conceptualisation of results denotes the relevance of the outcomes of this review for researchers, clinicians, community organisations, policy makers and children with disabilities and their families.

2.6 CONCLUSION

This scoping review demonstrates the interrelatedness of personal, environmental and activity-related elements in creating meaningful participation experiences for children and youth with disabilities. This review reveals the substantial contribution that meaningful interactions and relationships have in creating and facilitating positive and engaging experiences. Knowledge derived from this review may assist practitioners when considering the core environment-focused and person-based
components of intervention designs to improve leisure participation outcomes in children and youth with disabilities.

2.6.1 IMPLICATIONS FOR REHABILITATION

- Elements identified in this review may operate as core components of interventions that aim to optimise participation outcomes in community-based leisure activities.
- Supportive relationships and the availability of services are specific aspects of the environment that need to be considered by health professionals to facilitate participation.
- Understanding the perspectives of the child is critical for assessing needs, preferences and goals relating to leisure participation in the community.

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DECLARATION OF INTEREST:

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2.7 References


Chapter Three

Enabling physical activity participation for children with disabilities following a goal-directed, family-centred intervention

This manuscript was submitted for publication in Research in Developmental Disabilities, in November 2016, and is currently under review:


The PhD candidate, Claire E Willis, accounted for 50% of the intellectual property associated with the final manuscript (the individual responsible for data analysis, interpretation, and manuscript preparation and revision). Collectively, the remaining authors contributed 50% (including study design and data collection, and revision of the draft manuscript). The formatting and references of this chapter follow the guidelines for submission to Research in Developmental Disabilities.
As outlined in Chapter One, there is a dearth of literature describing interventions specifically targeted at enhancing participation in physical activity for children and youth with disabilities. Exercise programmes, although beneficial, typically examine participation as a secondary outcome and demonstrate little effect on this domain. There is also no documented evidence of physical activity interventions that are family-centred, goal-directed, and engage community resources, approaches of which may be effective at optimising participation and long term outcomes for children and families.

The following four chapters of this thesis are centred on the evaluation of the Local Environment Model (LEM) intervention at Beitostolen Healthsports Centre (BHC) in Norway (see Appendix A for the detailed description of the intervention). The LEM is goal-directed and family-centred, with emphasis on cooperation, education and resource capacity building in partnership with local communities. This chapter addresses the first question of complex intervention evaluation, to determine whether the intervention works in everyday clinical practice, with participation the primary outcome. Additionally, this chapter explores factors affecting ongoing participation in physical activity following the intervention. This paper presents new knowledge surrounding the outcomes of goal-directed and family-centred interventions to enhance physical activity participation outcomes, and contributes recommendations for the measurement of participation for future studies.
3.1 ABSTRACT

**Background:** Facilitating participation in physical activity for children with disabilities is recognised as an urgent priority.

**Aim:** To evaluate changes in physical activity participation in children with disabilities following a goal-directed intervention at a healthsports centre, and to identify factors influencing participation following the intervention.

**Methods and Procedures:** A mixed methods pre-test post-test quasi-experimental design was applied. Recruitment occurred over a 12 month period during standard clinical service provision. The Canadian Occupational Performance Measure (COPM) was administered to children and parents pre (T1) and post-intervention (T2), and at 12 weeks follow-up (T3). Goal Attainment Scaling (GAS) was applied to assess outcomes at 12 weeks follow-up (T2-T3). Qualitative inquiry described barriers to goal attainment at T3.

**Outcomes and Results:** Ninety two children with a range of disabilities (mean age 11.1yr; 49 males) showed statistically significant improvements in parent ratings of COPM performance and satisfaction of physical activity goals following intervention. Ratings at 12 weeks follow-up remained significantly higher than baseline, and 32% of children attained their COPM-derived GAS goal. Environmental factors were the most frequent barrier to goal attainment following intervention.

**Conclusion and implications:** These results provide evidence for goal-directed, family-centred interventions to enable physical activity participation for children with disabilities.
3.2 INTRODUCTION

Enabling participation in physical activity is an important goal for children and youth with disabilities, parents and health professionals. It is widely acknowledged that children and youth can experience health and psychosocial benefits from regular participation in physical activity. However, children and youth with disabilities are more restricted in their physical activity participation than their typically developing peers (Maher, Williams, Olds, & Lane, 2007; Van den Berg-Emons et al., 1995), and are less active as they become older (MacDonald, Esposito, & Ulrich, 2011). The need to identify strategies that facilitate meaningful involvement in physical activity is recognised as an urgent priority (Peterson, 2015).

A range of environmental, personal and activity-related barriers and facilitators affecting physical activity participation in children and youth with disabilities have been identified (Kang, Zhu, Ragan, & Frogley, 2007; Lin et al., 2010; Shields, Synnot, & Barr, 2011; Verschuren, Wiart, Hermans, & Ketelaar, 2012). Shields et al. (2011) demonstrated that children most commonly described personal, peer-related and environmental barriers to physical activity participation, including preferences for other activities, negative behaviour of peers and a lack of adaptive equipment. Parents more frequently identified barriers and facilitators relating to the quality and availability of programmes and staffing (Shields et al., 2011). Recently, emphasis has been placed on the importance of focusing on the environment to enable a child’s participation (Darrah et al., 2011; Law, Anaby, Imms, Teplicky, & Turner, 2015), increasing accessibility, decreasing negative attitudes, and ensuring staff are adequately trained to adapt activities for children and youth if required (Verschuren, Wiart, & Ketelaar, 2013). Furthermore, it has been suggested that attempts to increase children’s activity should target the whole family (Timperio, Salmon, & Ball, 2004).

There is a strong evidence base in the paediatric rehabilitation literature that supports the efficacy of goal-directed and family-centred interventions to enhance outcomes across all domains of the International Classification of Functioning, Disability and Health (ICF) (Novak et al., 2013). Combined use of the Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS) has been suggested as beneficial in the assessment of outcomes in paediatric rehabilitation interventions, as they provide different but complementary information about clients’ goal progress (Cusick, McIntyre, Novak, Lannin, & Lowe, 2006; Keenan, King, Curran, & McPherson, 2014). These measures enable the development of personalised outcomes, with the COPM also able to be utilised as a self- and proxy-report measure. The COPM and the GAS have previously been employed as outcome measures in interventions targeting leisure participation in
children and youth with disabilities (Imms, Mathews, Nicola Richmond, Law, & Ullenhag, 2015; Law et al., 2015).

While exercise programs for children with disabilities have become a contemporary focus of intervention, limited studies have demonstrated improvements in the participation outcomes of participants. A recent systematic review by (Adair, Ullenhag, Keen, Granlund, & Imms, 2015) concluded that exercise programmes, whereby participation was a secondary outcome, generally demonstrated little effect on this domain. This review also reported that few intervention studies have focused on participation as a primary outcome measure. Although we know that exercise programs can be beneficial in children with disabilities, training interventions alone are not enough for them to stay physically active (Claassen, et al., 2011; Zwinkels, et al., 2015). Currently, there are limited studies that demonstrate the optimisation and maintenance of an individual’s physical activity participation at a community level, and in the long-term (Van der Ploeg et al., 2006; Van der Ploeg et al., 2007).

The purpose of this study was to evaluate change in physical activity participation following a goal-directed, family-centred intervention in children and youth with a disability immediately post-intervention and at 12 weeks follow-up. We hypothesised that i) the intervention will increase perceived (parent and child) performance and satisfaction of individual physical activity participation goals post intervention (T2) and at 12 week follow up (T3); and ii) children will attain goals relating to physical activity participation in their local community set post-intervention (T2). Additionally, we aimed to explore the factors affecting goal attainment in a child’s local environment following intervention (T2 – T3), as reported by the parent.

3.3 METHODS

3.3.1 STUDY DESIGN

A pre-test post-test quasi-experimental design was used to determine changes in physical activity goal attainment, performance and satisfaction following a child’s participation in the Local Environment Model (LEM) intervention at Beitostolen Healthsports Centre (BHC), and to determine whether participation outcomes achieved from the intervention could be transferred into the child’s local community. This study was an evaluation of a clinical program that has longitudinal outcome measurement embedded within it. Ethics approval for this study was obtained from the Norwegian
Regional Committee for Medical and Health Research Ethics, section South-East C (S-08658a 2008/18016), and The University of Western Australia (RA/4/1/8263).

3.3.2 PARTICIPANTS

Recruitment occurred over a 12 month period using consecutive sampling during standard clinical service provision at BHC. Children were eligible to participate in this study if they were a) participating in a stay at BHC in a Local Environment Model group, b) between 6 and 17 years of age, and c) had parents who also consented to participate. Eligibility criteria for participating in the LEM are broad and non-specific (i.e. children aged 6-17 years with activity limitations and participation restrictions, as identified by a medical practitioner), thus no disability types were excluded.

3.3.3 DESCRIPTION OF INTERVENTION

BHC is a specialist rehabilitation centre in Norway, seeking to enhance lifelong activity and participation for children with disabilities in their local environments (Dalen, Nyquist, Saebu, Roe, & Bautz-Holter, 2013). Using an ecological model, rehabilitation programs at BHC are designed to change the characteristics of the task and/or environment as a means of facilitating participation in physical activities in their communities. The LEM intervention is underpinned by principles of adapted physical activity (Hutzler & Sherrill, 2007) and situated learning theory (Lave & Wenger, 1991). The intervention is considered a learning process, with focus on the development of skills and perceptions of competence. The LEM is goal-directed and family-centred, with emphasis on cooperation with local communities to facilitate long-term physical activity participation.

Before the commencement of the program, a field team (of physiotherapists and adapted physical activity specialists from BHC) travels to the local community of the children’s group coming to stay at BHC. The purpose of this meeting is to engage children, parents, and local service providers (physiotherapists, occupational therapists, teachers, teaching assistants) from the same municipality in the preparation, intervention and follow-up stages of service delivery.

The intervention is delivered at BHC, where groups of 8-10 children and their parents stay for 19 days. The intervention is intensive, consisting of physical, social and cultural activities, and extensive use of the outdoor facilities 2-5hrs a day, six days a week. The intervention is based on the child’s goals (e.g. learning to ski), but also designed to introduce children and their families to new and
different physical activities and participation experiences (e.g. rock climbing). During the stay, parents participate in a specially designed ‘Parental Guidance Program’, that provides knowledge and training about how they can facilitate their child’s participation at home by making changes to their environment. Additionally, local service providers of each child are invited to participate in a short training course designed to educate about strategies to adapt environments, and to connect service providers from the same municipality to encourage collaboration. These programs are designed to emphasise the important role of parents and local service providers as facilitators to their child’s participation.

Twelve weeks after families return to their local communities, the same field team travels back to the community. The primary objective of this meeting is to map each child’s progress towards achievement of their goals, and discuss any barriers families may still be facing in accomplishing this.

3.3.4 Measures

3.3.4.1 The Canadian Occupational Performance Measure (COPM)

The COPM (Law et al., 1990) is a clinical assessment tool used to identify client priorities in everyday tasks. Using a semi-structured interview, the COPM is a five step process which measures individually-identified focus areas in self-care, productivity, and leisure. The COPM rating scales use a 10-point scale, with a higher score reflecting a perceived better performance and increased satisfaction. A change of at least two points is considered clinically significant (Law et al., 1990). Adequate validity, excellent test-retest reliability and responsiveness to change of the COPM has been reported (Dedding, Cardol, Eyssen, & Beelen, 2004; Law et al., 1994).

3.3.4.2 Goal Attainment Scale (GAS)

The GAS is an outcome tool that assesses the extent to which an individual’s goals are achieved in the course of intervention (Kiresuk, Smith, & Cardillo, 1994). The procedure involves defining five levels of possible outcomes for the specified goal. The levels range from the individual’s current level (-2), to the level of achievement that would exceed expectations but is believed to be possible for that individual (+2). The middle level (0) represents the expected level of attainment after intervention. The GAS is reported in normalized T scores; a score of 50 corresponds to the achievement on the ‘0’ level (i.e. goals, on average, are achieved) (Kiresuk et al., 1994).
A strength of both the GAS and COPM is their highly individualized nature, allowing participants with different goals and health conditions to be compared on the basis of goal achievement. Both measures are considered to be client-centred (Donnelly & Carswell, 2002), with good responsiveness (Donnelly & Carswell, 2002), sensitivity to change (Cusick et al., 2006), and good reliability and validity (Donnelly & Carswell, 2002).

### 3.3.4.3 Qualitative Inquiry

During the GAS rescore at follow-up (T3), an open-ended interview was conducted with parents of children who did not reach their expected level of goal attainment (i.e. GAS score of -2 or -1). Parents were asked to describe what (if any) barriers affected the attainment of the GAS goal.

### 3.3.5 Procedure

Outcome assessments were conducted at baseline (T1), end of intervention (T2) and at 12 weeks follow-up (T3) (Fig. 3.1).

![Figure 3.1 Timeline of assessment.](local:images/figure3_1.png)

CAPE, Children’s Assessment of Participation and Enjoyment; PAC, Preferences for Activities of Children; COPM, The Canadian Occupational Performance Measure; GAS, Goal Attainment Scaling.

At T1, children (in collaboration with their parent/primary caregiver) identified three of their most important participation goals using the COPM. The goals were based on the outcomes of the Norwegian version (Nordtorp, Nyquist, Jahnsson, Moser, & Strand, 2012) of the Children’s Assessment of Participation and Enjoyment (CAPE) (King et al., 2004) and the Preferences for Activities of Children (PAC) (King et al., 2006), and identified aspirations for physical activity participation at home, at school and/or in their local community. Parents and children completed the COPM with an experienced occupational therapist, physiotherapist or sports pedagogue. Parents completed the standard COPM using a 10-point scale. Children used a simplified (non-validated) 5-point scale to indicate performance and satisfaction, an attempt to make the self-report process a
possibility for as many children as possible. Parents and children rated the same goals and were blinded to each other’s scores.

The intervention was developed by the administering therapists, according to the children’s individual goals within each group. Subsequently, the type of activities delivered in the intervention was not the same between each LEM group. The dosage of intervention was the same between all LEM groups; 2-5hrs a day, six days a week, for 19 days.

At the end of the intervention (T2), the COPM was administered to each child and their parent (rating the same goals but completed separately) to monitor their level of performance and satisfaction of their physical activity participation goals. Parents and children were blinded to their previous response.

Using their responses to the COPM at T2, participants identified a physical activity participation focus for their return home collaboratively with families and administering therapists at BHC (King, McDougall, Palisano, Gritzan, & Tucker, 2000). To highlight the focus of ongoing goal-directed physical activity participation in the families’ local environment after the rehabilitation stay, one individualised goal was determined for each child using the GAS.

Follow up COPM and GAS outcomes were evaluated 12 weeks post-intervention (T3). The COPM satisfaction and performance ratings of all three original physical activity goals were repeated individually by parents and children, again blinded to previous responses. The GAS goal was re-scored by the child and parent in collaboration with the primary researcher or by a therapist who did not deliver the intervention (King et al., 2000; Kiresuk et al., 1994).

3.3.6 Statistical Analysis

Analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 23. Descriptive statistics were used to summarise participant characteristics. Due to the non-parametric nature of the COPM data, Friedman tests were used to compare performance and satisfaction medians over time. Post hoc analysis with Wilcoxon signed-rank tests were conducted with a Bonferroni correction applied (significance level set at p=0.01). Effect sizes were determined for statistically significant comparisons by using Pearson’s r calculation ($r=\frac{z}{\sqrt{N}}$), with a value of 0.5 considered a large effect, 0.3 a medium effect, and 0.1 to be a small effect (Cohen, 1992).
Wilcoxon signed rank tests were applied to post-test GAS T-scores to determine any significant difference from the expected mean (T=50). Secondary analysis was conducted by collapsing the GAS data into two categorical variables (achieved GAS goal, T=≥50; and, did not achieve GAS goal, T=≤40). Mann-Whitney U tests were used to determine any differences in COPM performance and satisfaction ratings (T3) between children who did and did not achieve their GAS goal during the follow-up period.

A framework approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013) informed by the ICF was applied to qualitative data to identify the barriers associated with goal attainment in local communities. Open coding methods were used to classify responses, with similar codes merged and synthesised upon review. Refined codes were categorised into ICF components to describe the main factors influencing goal attainment. The coding procedure was performed individually by two of the study authors, with any uncertainties resolved by discussion until consensus was reached.

3.4 Results

All children and parents participating in the study provided informed consent. Ninety two of 111 eligible children were included in the sample (82% retention). These children had GAS data at 12 weeks follow up (T3). For eighty of these children, parents had rated the child’s satisfaction and performance level (COPM) of the goal activity for all three time points (T1-T3). Sixty-one children had also been able to independently complete the 5-point COPM at all time points (Fig. 3.2).
Demographic information of the 92 children (43 females and 49 males) who completed the study is outlined in Table 3.1. Children had a mean age of 11 y 1 m (SD 2 y 8 m) and had a range of disabilities. Disabilities with the highest representation in the sample included cerebral palsy (48%) and intellectual disability (26%). Thirty nine percent reported current use of a leisure support person in their local community. Data was recorded regarding the location type of 44 of the 92 children; 16.7% resided in a city, 62.5 percent in a rural town, and 20.8% in a remote village.
Table 3.1 Participant demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n=92</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y:mo (SD)</td>
<td>11:1 (2:8)</td>
</tr>
<tr>
<td>Age range, y</td>
<td>6-17</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49 (53%)</td>
</tr>
<tr>
<td>Female</td>
<td>43 (47%)</td>
</tr>
<tr>
<td>Child's primary health condition, n (%)</td>
<td></td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>44 (48%)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>24 (26%)</td>
</tr>
<tr>
<td>Other neurological and neuromuscular disorders</td>
<td>16 (17%)</td>
</tr>
<tr>
<td>Pervasive and specific developmental disorders</td>
<td>8 (9%)</td>
</tr>
<tr>
<td>Leisure support person, n (%)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>36 (39%)</td>
</tr>
<tr>
<td>No</td>
<td>56 (61%)</td>
</tr>
<tr>
<td>Family type, n (%)</td>
<td></td>
</tr>
<tr>
<td>Lives with both parents</td>
<td>65 (71%)</td>
</tr>
<tr>
<td>Lives with one parent</td>
<td>20 (21%)</td>
</tr>
<tr>
<td>Foster care, other</td>
<td>7 (8%)</td>
</tr>
</tbody>
</table>

*a including muscular dystrophy, spina bifida and neural injuries

3.4.1 COPM

Using the Friedman test, there was a significant difference in parent ratings of COPM performance ($\chi^2 (2, n=80) = 73.12, p<0.01$) at baseline (T1), end-of-intervention (T2) and at 12 weeks follow up (T3) (Fig. 3.3). Post hoc analysis using Wilcoxon signed-rank tests indicated a significant difference in performance between T1 and T2 ($Z = -7.24, p<0.01$), with a large effect size ($r=0.81$). A significant difference in performance ratings between T1 and T3 ($Z = -6.67, p<0.01$), with a large effect size ($r=0.74$), was also observed. There was no significant difference in performance ratings between the end of intervention (T2) and 12 weeks follow up (T3). Median COPM performance ratings across the three time points (T1-T3) were 5.0, 7.0 and 6.8, respectively.

Significant differences were also observed in parent ratings of COPM satisfaction ($\chi^2 (2, n=80)= 73.32, p<0.01$) across the three time points (T1-T3) (Fig. 3.3). Satisfaction ratings showed a significant difference between T1-T2 ($Z = -7.32, p<0.01$), with a large effect size ($r=.82$), and between T1-T3 ($Z = -6.19, p<0.01$), also with a large effect size ($r=0.69$). There was a significant difference in ratings of satisfaction between the end of intervention and at follow up ($Z=-3.38, p=0.01$) with a medium effect size ($r=.38$). This was not considered a clinically significant change (a difference of 2
points or more) in 70 out of the 80 parents. Median COPM satisfaction ratings across the three time points (T1-T3) were 5.3, 8.0 and 7.7, respectively.

**Figure 3.3** Parent-rated Canadian Occupational Performance Measure (COPM) performance and satisfaction scores over time. *within group difference p<0.01.

**Figure 3.4** Child-rated Canadian Occupational Performance Measure (COPM) performance and satisfaction scores over time. *within group difference p<0.01.
As rated by the child on the 5-point scale, the Friedman test demonstrated a statistically significant difference in ratings of performance across the three time points $\chi^2 (2, n=61) = 49.87, p<0.01$). Post hoc analysis using Wilcoxon signed-rank tests showed significant differences in performance ratings between T1-T2 ($Z = -5.92, p<0.01$) with a large effect size ($r=0.76$), T1-T3 ($Z= -4.86, p<0.01$) with a large effect size, and between T2-T3 ($Z= -3.07, p=0.002$), with a medium effect size ($r=.39$). Median performance ratings using a 5-point scale across the three time points (T1-T3) were 3.3, 4.3 and 4.0, respectively (Fig. 3.4).

There were statistically significant differences in child-ratings of satisfaction $\chi^2 (2, n=61) 45.87, p<0.01$) across the three time points (Fig. 3.4). Post hoc analysis showed significant differences in ratings of satisfaction between T1-T2 ($Z = 5.35, p<0.01$), with a large effect size ($r=0.69$). Significant differences were also observed between T1-T3 ($Z = -4.85, p<0.01$), with a large effect size ($r=.62$). According to the child-ratings, there was no significant difference in ratings of satisfaction between T2-T3. Median satisfaction ratings using a 5-point scale across the three time points (T1-T3) were 3.7, 4.3 and 4.3, respectively.

### 3.4.2 GAS

Each child identified one primary goal at T2 for their return home, with a combined total of 92 measured GAS goals. For 75 children, their GAS goal was derived from their initial COPM. The remaining 17 children chose a new goal (based on their exposure to new activities during the course of their stay at BHC) to work towards upon return to their local communities.

All GAS goals were related to participation in physical activity. Fifty five percent of goals were pool-based and swimming activities, 11% bike and cycling activities, 9% activities in the snow (e.g. alpine skiing, cross country skiing), 8% activities in a sports hall (e.g. el bandy, school games), 8% horse riding, 4% rock climbing and the remaining 5% were classified as ‘other outdoor land and water activities’ (e.g. boating).

#### 3.4.2.1 Goal Attainment

The GAS T-scores for this analysis had a possible range from 30-70, with an expected mean of 50. Thirty two percent of children achieved a T-score equal to or greater than 50, indicating their achievement of the expected, more than expected, or much more than expected outcome on their participation goal in their home community. Fifty seven percent of children made some progress (T
≥40) towards their GAS goal. According to Wilcoxon signed rank tests, the median post-test T-score (md=40.0) was significantly lower than the expected mean of 50 (Z = -5.95, p<0.01). Characteristics of participants in relation to post-test T-scores can be seen in Table 3.2.
Table 3.2 GAS T-scores at 12 weeks follow up

<table>
<thead>
<tr>
<th>GAS score at 12w follow-up</th>
<th>Much less than expected</th>
<th>Less than expected</th>
<th>Expected outcome</th>
<th>More than expected</th>
<th>Much more than expected</th>
</tr>
</thead>
<tbody>
<tr>
<td>T=30</td>
<td>40 (43%)</td>
<td>23 (25%)</td>
<td>22 (24%)</td>
<td>2 (2%)</td>
<td>5 (6%)</td>
</tr>
<tr>
<td>Age, y:mo (SD)</td>
<td>11:3 (2:6)</td>
<td>11:0 (3:0)</td>
<td>11:3 (2:7)</td>
<td>8:0 (1:5)</td>
<td>9:0 (2:5)</td>
</tr>
<tr>
<td>Age range, y</td>
<td>7-16</td>
<td>6-17</td>
<td>7-16</td>
<td>7-9</td>
<td>6-12</td>
</tr>
<tr>
<td>Gender n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>20 (50%)</td>
<td>17 (74%)</td>
<td>9 (41%)</td>
<td>1 (50%)</td>
<td>2 (40%)</td>
</tr>
<tr>
<td>Female</td>
<td>20 (50%)</td>
<td>6 (26%)</td>
<td>13 (59%)</td>
<td>1 (50%)</td>
<td>3 (60%)</td>
</tr>
<tr>
<td>Diagnostic group, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>19 (48%)</td>
<td>11 (48%)</td>
<td>11 (50%)</td>
<td>1 (50%)</td>
<td>2 (40%)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>12 (30%)</td>
<td>5 (22%)</td>
<td>6 (27%)</td>
<td>0</td>
<td>1 (20%)</td>
</tr>
<tr>
<td>Other neural, neurological and neuromuscular disorders</td>
<td>5 (12%)</td>
<td>6 (26%)</td>
<td>3 (14%)</td>
<td>0</td>
<td>2 (40%)</td>
</tr>
<tr>
<td>Pervasive and specific developmental disorders</td>
<td>4 (10%)</td>
<td>1 (4%)</td>
<td>2 (9%)</td>
<td>1 (50%)</td>
<td>0</td>
</tr>
<tr>
<td>Leisure support person n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21 (52%)</td>
<td>8 (35%)</td>
<td>6 (27%)</td>
<td>0</td>
<td>1 (20%)</td>
</tr>
<tr>
<td>No</td>
<td>19 (48%)</td>
<td>15 (65%)</td>
<td>16 (73%)</td>
<td>2 (100%)</td>
<td>4 (80%)</td>
</tr>
<tr>
<td>Family type n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives with both parents</td>
<td>29 (72%)</td>
<td>15 (65%)</td>
<td>15 (68%)</td>
<td>2 (100%)</td>
<td>4 (80%)</td>
</tr>
<tr>
<td>Lives with one parent</td>
<td>9 (23%)</td>
<td>5 (22%)</td>
<td>5 (23%)</td>
<td>0</td>
<td>1 (20%)</td>
</tr>
<tr>
<td>Foster care, other</td>
<td>2 (5%)</td>
<td>3 (13%)</td>
<td>2 (9%)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

GAS, Goal Attainment Scale; SD, standard deviation.
Following the categorisation of GAS data, Mann Whitney U tests indicated no significant difference in COPM performance (p=0.126) or satisfaction (p=0.934) scores between children who achieved their GAS goal (n=26) and children who did not achieve their goal (n=54).

3.4.2.2 Barriers to Participation in Local Communities

Qualitative data regarding barriers to participation and/or reasons for not attaining expected outcomes was captured from the 51 of the 63 participants with GAS rescores of -2 (n=40) or -1 (n=23). The two coding authors (CW, AU) agreed on 98% of the codes, with the discrepancies resolved through discussion. Eleven of the 23 participants with a T-score of 40 reported that they were satisfied with their current level of goal attainment. Along with one participant with missing data, these participants did not contribute to this qualitative sample (n=51).

Data of participants with much less or somewhat less than expected outcomes who were experiencing barriers to goal attainment is presented in Table 3.3. Environmental factors were the main barrier described by 61% of participants. Body function and structure-related barriers were identified by 25% of participants. Seven participants indicated that they were currently participating in active leisure activities, but no longer working towards their identified GAS goal.

Table 3.3 Barriers related to goal attainment at follow-up, described by 51 participants who did not attain their GAS goal.

<table>
<thead>
<tr>
<th>ICF component</th>
<th>Barrier to goal attainment</th>
<th>n/51 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body functions and structures</td>
<td>Illness</td>
<td>7 (14%)</td>
</tr>
<tr>
<td></td>
<td>Surgery/medical procedure</td>
<td>4 (7%)</td>
</tr>
<tr>
<td></td>
<td>Motivation</td>
<td>2 (4%)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>13 (25%)</td>
</tr>
<tr>
<td>Activity and participation</td>
<td>Participating, but not working towards specific GAS goal</td>
<td>7 (14%)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7 (14%)</td>
</tr>
<tr>
<td>Environment</td>
<td>Access to services and equipment</td>
<td>14 (27%)</td>
</tr>
<tr>
<td></td>
<td>Climate/seasonal</td>
<td>8 (16%)</td>
</tr>
<tr>
<td></td>
<td>Lack of support/guidance</td>
<td>5 (10%)</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>3 (6%)</td>
</tr>
<tr>
<td></td>
<td>Friends do not participate in this activity</td>
<td>1 (2%)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>31 (61%)</td>
</tr>
</tbody>
</table>

ICF, International Classification of Functioning, Disability and Health; GAS, Goal Attainment Scale
3.5 DISCUSSION

Our results support the use of goal-directed interventions to improve physical activity participation in children and youth with disabilities. Significant improvements on COPM performance and satisfaction were observed following intervention at BHC. At 12 weeks follow up, these outcomes were generally maintained. Environmental factors were described by participants as the most common barrier to goal attainment in their local communities. These results are in line with previous goal-directed interventions in paediatric disability (Imms et al., 2015; Law, et al., 2015; Novak et al., 2013). This is one of the first studies to evaluate participation as the primary outcome measure in a physical activity intervention in children and youth with disabilities.

Our results reveal positive trends in physical activity participation in a child’s home community following intervention at a healthsports centre. Improvements in performance and satisfaction achieved during the intervention were typically maintained at 12 weeks follow-up. Whilst children indicated a significant decrease in their perceived performance at 12 weeks follow-up, there was no significant difference in their ratings of satisfaction of this performance compared to post-intervention. The intervention at the healthsports centre, with focus on developing skills and activity competence, may assist in improving the self-efficacy of the child in their performance of the goal activity in other environments. Ten parents reported a decrease in satisfaction ratings at follow-up that was considered clinically significant (with no difference in performance), which may be a result of expectations that arise from observing the possibilities that exist at the healthsports centre that may not exist at a service level in local communities. Encouragingly, both child- and parent-rated performance and satisfaction scores at follow up remained significantly higher than at baseline. The results of this study add to the promising results of the growing number of interventions enhancing participation for children and youth with disabilities. Both Law et al. (2015) and Imms et al. (2015) have recently described interventions that changed aspects of only the activity or environment to improve youth participation in leisure activities. Our large sample size and group-based approach are a unique addition to this growing evidence-base of environment-focused interventions.

Despite the results demonstrated in the COPM, only 32% of children in this study achieved a T-score of zero or above (expected, or greater than expected level of achievement) on their GAS at 12 weeks follow-up. Importantly, 57% of children made some progress (T ≥40) towards their GAS goal. These results may suggest that the ‘0’ score (expected outcome) on the GAS exceeded what was possible to achieve in 12 weeks. Qualitative inquiry at follow up described that almost half of participants who did not attain expected outcomes (as rated by the GAS at follow up) were satisfied with their current
progress towards their physical activity goal, or were participating in physical activities not specified on the GAS. A significant focus of the intervention at BHC is dedicated to introducing children and their parents to new and different physical activities. Thus, upon leaving the centre, families are equipped with the knowledge and skills of enabling participation across a variety of physical activities. This may explain why a portion of children were participating in an alternative physical activities other than that outlined in their GAS. Measuring the multiple dimensions of participation (Imms et al., 2016) in addition to goal attainment, and employing longer follow-up periods within the study design, may be necessary to more accurately document changes in physical activity participation in future interventions.

Environmental factors were identified as the main barrier to goal attainment at 12 weeks follow-up. This is in line with the growing body of literature identifying environmental factors as a major determinant of the participation of children and youth with disabilities (Anaby et al., 2013). In this study, barriers relating to services in the community (access to services and equipment) were the most common environmental barrier described by children and families who did not reach their expected level of goal attainment following the intervention. Verschuren et al. (2013) have previously described that families who were classified into the intention and action stage of behavioural change (e.g. families participating in an intervention) were more likely to identify environmental barriers related to the facility or program or the social environment than families at the pre-intention stage. Previous interventions intended at increasing community leisure participation for youth with disabilities also highlighted service-related barriers (e.g. registration fees) as a primary determinant to ongoing participation in activities (Law et al., 2015). These results highlight that it is equally important to ensure the accessibility of environments, and specifically services, to enhance the sustainability of physical activity habits acquired following interventions. Encouragingly, Zwinkels et al. (2015) have recently published their protocol of the ‘Sport to Stay Fit’ intervention to investigate if an after school sport program can sustain the positive effects of a standardised interval training intervention. Although outcome measures relate primarily to physical fitness (Zwinkels et al., 2015), enabling access to a community program after the intervention addresses key service-related barriers identified in our study, and others.

There is a paucity of literature describing interventions targeted at enhancing physical activity participation in children and youth with disabilities. Whilst it has become clear that the environment can serve as a target for intervention (as with our LEM intervention), the availability and accessibility of services are essential considerations in intervention design to enhance the sustainability of physical activity practices acquired from interventions. Furthermore, active participation in goal setting and
choice in meaningful activity may be essential for the physical activity behaviours children with disabilities adopt. Care must be taken in future studies to ensure that the goals constructed for interventions are framed as participation goals (and not activity or body function goals), if physical activity participation is the intended outcome (Imms et al., 2016; Imms et al., 2015). This was a strength of our intervention, with 100% of goals related to physical activity participation.

There are some limitations associated with this study. To increase the participation of children in the goal setting process, a five-point scale on the COPM was used. As this is not a standardised or validated version of the instrument, clinically significant changes in performance and satisfaction cannot be determined. However, the authors advocate for the child’s voice in to be included in participation measurement, thus these results were included. Additionally, obtaining information regarding functional level is not a part of standard clinical practice at BHC - anyone of any ability is able to participate, function is not a barrier nor a primary intervention target. Generally, if an individual has a leisure support person to assist their participation in community activities, it is indicative of a lower functional level. Almost 40% of children in this study had a leisure support person in their home community.

As there was no control group within the study design, it is not possible to separate the outcomes of intervention from other influencing effects. Using repeated measures throughout a longer follow-up period post-intervention would have strengthened the study by providing more information about goal attainment, especially as participants indicated high levels of satisfaction with their progress towards their goal at 12 weeks. Furthermore, obtaining information regarding the facilitators to goal attainment is equally as important as understanding the barriers. This is recommended for future studies.

A strength of this study was our large sample size. This, and the repeated replication of the effect of the intervention across different goals and environments enhances the generalisability of our results.

3.6 CONCLUSION

The results of this study demonstrate that a goal-directed, family-centred intervention improved the performance and satisfaction of participation in meaningful physical activities for children and youth with a disability. This study provides a unique insight into factors that influence physical activity goal attainment following intervention at a healthsports centre. Environmental factors, particularly those related to service accessibility, were identified as a primary barrier to physical activity participation.
in community settings. Results from this study can be used to inform health professionals and researchers about the effectiveness of goal-directed interventions to optimise physical activity participation in children and youth with disabilities.

ACKNOWLEDGMENTS

We wish to thank Team Leader Anita Hoberg (MSc PT) and members of the multidisciplinary paediatric teams that assisted in the data collection process. In addition, we wish to thank Dr Håkon Dalen (Head of Department, MD), Sports Pedagogue Inge Morisbak (Former Head of Research Department, MSc), Professor Thomas Moser, and Dr Siobhan Reid for their valuable contributions and discussions. A Princess Margaret Hospital Foundation scholarship supported the first authors’ time compiling this article. The authors have stated that they had no interests which might be perceived as posing a conflict or bias.


Chapter Four

‘Capturing the magic’: Identifying the active ingredients of a physical activity participation intervention for children and youth with disabilities

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The PhD candidate, Claire E Willis, accounted for 80% of the intellectual property associated with the final manuscript (the primary individual involved in the study design, data collection, data analysis, data interpretation, and manuscript preparation and revision). Collectively, the remaining authors contributed 20%. The formatting and references of this chapter follow the guidelines for submission to Clinical Rehabilitation.
Chapter Three of this thesis established that the LEM intervention at BHC improved the performance and satisfaction of participation in meaningful physical activities for children and youth with a disability, with positive trends in ongoing participation in home communities following the intervention. Given these encouraging findings, it was important to answer the second question of complex intervention evaluation: how and why does the intervention work? Chapter Four, Five and Six describe these findings, from the perspectives of BHC staff and local paediatric service providers, children, and parents, respectively. Data collection for these studies was completed simultaneously using an ethnographic approach, comprising three phases throughout 15 weeks in the field.

The third study presented in this thesis aimed to identify the active ingredients of the LEM at BHC, from the perspectives and practices of staff at BHC and visiting paediatric service providers. Understanding the active ingredients from professionals involved in the delivery in the intervention assisted in the development of operational definitions, which may promote consistency across practitioners at the level of actual service delivery in any future implementation. Further, linking the findings to the ICF-CY gives the study wider applicability. This chapter highlights important implications for future intervention designs, outlining ingredients that may encourage more participation-focused outcomes for children and families.
4.1 **Abstract**

*Aim:* This study aimed to define the active ingredients of an intervention that facilitates physical activity participation for children and youth with disabilities, and develop operational definitions to support implementation in other settings.

*Methods:* An ethnographic approach was employed, triangulating participant observation, interviews and focus groups over 15 weeks in the field. Participant recruitment occurred through purposive sampling of staff employed at Beitostolen Healthsports Centre (BHC), and paediatric service providers visiting the centre who resided in various locations around Norway. Interviews were transcribed verbatim and coded together with observation data. Secondary coding linked data to corresponding categories of the International Classification of Functioning, Disability and Health: Child and Youth version.

*Results:* Thirteen staff from BHC and seven paediatric service providers participated in the study. Fourteen active ingredients were identified, and were characterised as intervention design (n=8), the environment (n=4), and the effect on the individual (n=2). Within the ingredients, meaning units were linked to 53 unique ICF-CY categories and components; 26 categories belonged to the component of ‘environment’, 26 categories to ‘activities and participation’, and while no distinct categories, the component ‘personal factors’. No categories related to ‘body function’ or ‘body structures’.

*Conclusion:* The role of the environment, and specifically support and relationships, is an essential consideration for enabling physical activity participation. Outcomes may guide future program design for the promotion and sustainability of practices following interventions.
Enabling participation is often described as the ultimate outcome in health interventions.\(^1\) The International Classification of Functioning, Health and Disability Child and Youth version (ICF-CY) defines participation as ‘involvement in a life situation’.\(^2\) Imms et al.\(^3\) clarifies this, specifying the participation experience as two elements: attendance and involvement. Attendance is a necessary prerequisite to involvement, and the activities that children attend must accommodate the child’s preferences and activity competence if they are to be experienced as meaningful.\(^3\) However, literature describing evidence-based approaches to improving participation in children and youth with disabilities is limited.\(^4\)

Participation in physical activity is necessary for the optimal physical, emotional, and psychosocial development of all children and youth. Yet, children and youth with disabilities are less active than their typically developing peers\(^5\), and are reported to spend 76% to 99% of their waking hours sedentary.\(^6\) Identifying strategies that facilitate involvement in physical activity for children with disabilities is currently recognised as an urgent priority.\(^7\) Few exercise interventions have demonstrated changes in participation outcomes\(^4\), and low levels of participation in physical activities at home and in the community are frequently reported.\(^8, 9\) Our challenge lies in the development of approaches whereby physical activity practices acquired from interventions can be translated into long term participation and lifelong habits. However, evidence of strategies that may facilitate this within intervention design is lacking.\(^10\)

Following the widespread adoption of the ICF-CY, much paediatric rehabilitation research involves the evaluation of what are considered ‘complex interventions’. Complex interventions are described as those that involve a number of interacting components, allow for flexibility or individualisation of implementation, and contribute to a variety of outcomes.\(^11\) The key question in evaluating complex interventions is, does it work (i.e. is there change in the targeted ICF-CY levels)?\(^9,11\) Such interventions are often criticised as being a ‘black box’, as it can be difficult to know why the intervention worked (or not) without examining underlying processes.\(^12\) Thus the second key question, and one that is answered less often, is, what are the active ingredients that maximise outcomes (i.e. what makes the intervention work)?\(^9,11\) Active ingredients may include specific treatment parameters, such as treatment dosage or intensity, or more general factors, such as therapist–child interaction.\(^13\) Further, operational definitions of the active ingredients should be developed to allow the intervention to be teachable, learnable and doable in other settings.\(^14\) Understanding how to capture, define and translate active
ingredients across interventions and settings is critical to the development of more effective interventions.\textsuperscript{15}

Qualitative research can be employed to show how and why an intervention works, and to identify potential barriers to change in interventions that seek to alter client or professional behaviour.\textsuperscript{16} Specifically, ethnographic methods have demonstrated utility in describing the process of change during an intervention, and how and why an intervention ‘works’.\textsuperscript{17, 18} Ethnography is described as the study of social interactions, behaviours, and perceptions that occur within groups, organisations, and communities.\textsuperscript{19} While its beginnings can be traced back to anthropological studies of small and rural societies\textsuperscript{19}, contemporary applications of ethnography have occurred in everyday settings, exploring the nature of a particular social phenomenon.\textsuperscript{20} This iterative process of continuous data collection, analysis and reflection make it possible to identify mechanisms that may enable the improvement and adaptation of interventions and services.\textsuperscript{21} Although ethnographic methods have been endorsed for the development and evaluation of health interventions\textsuperscript{17}, ethnography has been largely overlooked as a methodology for the in-depth study of health services.\textsuperscript{20}

Beitostolen Healthsports Centre (BHC) is a rehabilitation centre in the Jotunheimen mountain range in Norway, seeking to enable lifelong activity and participation in local environments for people with disabilities. Rehabilitation practices at the centre are based on theories of adapted physical activity\textsuperscript{22} and situated learning.\textsuperscript{23} An evaluation of the paediatric program at BHC (the Local Environment Model, LEM) demonstrated that the goal-directed, family-centred intervention improved the performance and satisfaction of participation in physical activities for children and youth with a disability and their parents, with these outcomes maintained at three months follow up.\textsuperscript{24} The overarching purpose of this study was to identify the active ingredients of the LEM at BHC. Specifically, we aimed to; (i) explore the perspectives and practices of staff at BHC and visiting paediatric service providers, to define the mechanisms by which the intervention may facilitate change; and (ii) develop operational definitions of these ingredients to support implementation in other settings.

4.3 METHODS

4.3.1 DESIGN

To identify the active ingredients of the LEM intervention at BHC, an ethnographic approach was adopted. As ethnography typically incorporates a range of methods\textsuperscript{20}, the triangulation of participant
observation, interviews and focus groups was used to explore the active ingredients and develop operational definitions.

Ethics approval for this study was obtained from the Princess Margaret Hospital Human Research Ethics Committee (2013099), The University of Western Australia (RA/4/1/6556), and the Norwegian Regional Committee for Medical and Health Research Ethics, section South-East C (2014/1342-1).

4.3.2 PARTICIPANTS

Participant recruitment occurred through purposive sampling of staff employed at BHC, and paediatric service providers visiting the centre who resided in various locations around Norway. This enabled the development of practice profiles at the level of actual service delivery, to promote consistency across practitioners in any future program implementation. Subsequent studies explore program mechanisms from the perspectives of children and families.

Staff at BHC were invited to participate in the study if they (i) were directly involved with service provision to children participating in the LEM; and (ii), had been employed at BHC for at least 12 months. Staff at BHC who met the inclusion criteria were first informed about the study by the Director of Paediatric Teams, prior to the first authors’ (CW) arrival at BHC. Following this, selected participants received a written information sheet.

Local paediatric service providers (LPSP) were invited to participate if they (i) had a professional relationship with a child participating in a stay at BHC; and (ii), were participating in the three day course for service providers offered by the centre. Service providers were informed about the study upon their arrival at BHC by the paediatric team leaders and were provided an information sheet if selected to participate.

4.3.3 DESCRIPTION OF INTERVENTION

BHC is a specialist rehabilitation centre in Norway, striving to enable participation in physical activity for people with disabilities. Programs are designed to change the characteristics of the task and/or environment, within a social context, as a means of facilitating the participation in physical activities. Specifically, the LEM focuses on co-operation, education and capacity building with children, parents
and local communities to facilitate long-term physical activity participation for children with disabilities.

A field team from BHC travels to the community of the children and families one month prior to their stay. The purpose of this meeting is to engage children, parents, and local paediatric service providers (e.g. physiotherapists and school teachers) from the same community in the preparation, intervention and follow-up stages of service delivery.

The intervention is delivered at BHC, where groups of 8-10 children and their parents stay for 19 days. The children’s stay at BHC is intensive, consisting of physical, social and cultural activities, 2-5hrs a day, six days a week. The intervention is based on the child’s goals (e.g. learning to ski), but also designed to introduce children and their families to new and different physical activities and participation experiences (e.g. rock climbing). Three children’s groups (6-17y), one young adult group (18-30y), and one adult group (>30y) stay at the centre and participate in their specific group program simultaneously.

During a child’s stay, parents participate in a specially designed ‘Parental Guidance Program’, that provides knowledge and training in relation to how to facilitate their child’s participation in their home and community. Additionally, LPSP involved with the child in their local communities are invited to participate in a short training course designed to educate about strategies to adapt environments, and to connect paediatric service providers from the same municipality to encourage collaboration. These programs are designed to emphasise the role of parents and LPSP as facilitators to a child’s participation.

Following the family’s’ return to their local communities, the same field team from BHC travels back to the community for a follow up meeting for children and their parents, and LPSP. This meeting is used to map each child’s progress towards achievement of their follow up plan, and discuss any barriers families may still be facing in accomplishing this. The region’s representative from the Norwegian Federation of Sport is also present at this meeting, so any problems that cannot be resolved can be followed up by local communities.

4.3.4 DATA COLLECTION

The first author (CW) spent a total of 15 weeks at BHC undertaking data collection, over two separate time periods (summer/autumn and winter/spring), accounting for any intervention-specific seasonal
differences that occur (e.g. activities, equipment). The first author lived at BHC, and participated in the daily work, social and leisure practices of staff and users of the Centre. Proficiency in the Norwegian language aided in the cultural immersion of the researcher.

Ethnographic fieldwork involved the triangulation of semi-structured interviews, focus groups and observation, employed over two time points. Interviews with staff were completed in phase 1, and interviews with service providers from around Norway occurred across all phases (Figure 4.1).

4.3.4.1 INTERVIEWS AND FOCUS GROUPS

The first author (CW; female, PhD candidate, and trained in qualitative research methods) undertook all interviews. Semi-structured interview guides were developed in collaboration with a steering group based in Australia. The steering group consisted of nine stakeholders; an adolescent with a disability, parents of children with a disability, clinicians (hospital-based and community providers), representatives from non-government organisations, and a disability policy maker. The interview guide was piloted with a manager at BHC to obtain feedback of utility prior to use in data collection. The interview guide covered broad topics for discussion and was revised when new topics were raised during the interviews. Topics discussed during the interviews with Staff at BHC and LPSP are outlined in Table 4.1.

**Figure 4.1** Timeline of data collection in weeks.
LPSP: Local paediatric service providers
Table 4.1 Key topics and prompts within semi-structured interview guide

<table>
<thead>
<tr>
<th>Staff at BHC</th>
<th>Local paediatric service providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model of service:</td>
<td>Model of service:</td>
</tr>
<tr>
<td>- Service, systems, and policies</td>
<td>- Experience in the LEM</td>
</tr>
<tr>
<td>- Physical activity program</td>
<td>- Needs of service providers</td>
</tr>
<tr>
<td>- Improvement/gaps in the service</td>
<td>- Improvement/gaps in the service</td>
</tr>
<tr>
<td>Environmental factors (BHC)</td>
<td>Environmental factors: (BHC vs. community)</td>
</tr>
<tr>
<td>- Support and relationships (for children, families and staff)</td>
<td>- Support and relationships (for LPSP)</td>
</tr>
<tr>
<td>- Natural and human-made environment</td>
<td>- Natural and human-made environment</td>
</tr>
<tr>
<td>- Products and technology</td>
<td>- Products and technology</td>
</tr>
<tr>
<td>- Attitudes</td>
<td>- Attitudes</td>
</tr>
<tr>
<td>Translation to local communities</td>
<td>Translation to local communities</td>
</tr>
<tr>
<td>- Role of families</td>
<td>- Barriers and facilitators</td>
</tr>
<tr>
<td>- Role of local communities</td>
<td>- Expectations of children and families</td>
</tr>
<tr>
<td>- Role of BHC</td>
<td>- Dissemination of knowledge</td>
</tr>
<tr>
<td>Person-based</td>
<td>Person-based</td>
</tr>
<tr>
<td>- Experience of role</td>
<td>- Impact on professional practice</td>
</tr>
<tr>
<td>- Satisfaction in role</td>
<td></td>
</tr>
<tr>
<td>- Needs of staff</td>
<td></td>
</tr>
</tbody>
</table>

BHC, Beitostolen Healthsports Centre; LEM, Local Environment Model; LPSP, local paediatric service providers

Semi-structured interviews explored the active ingredients of the LEM, based on the perspectives of professionals involved in and/or delivering the program. Interviews were conducted at a mutually convenient time in a private meeting room at BHC. Norway has very high proficiency in English, thus participants were offered the choice to conduct interviews in Norwegian or English. All participants elected to undertake interviews in English. At the time of the interview, the researcher was not known to staff. Interviews with staff ranged from 45-90 minutes in duration. Depending on the available time and preferences of the LPSP during their stay at BHC, interviews were conducted individually (n=2) or in a focus group setting (n=5). All interviews and focus groups were completed in 60 minutes. The first author transcribed each interview from the recordings verbatim. Copies of the transcripts were sent to participants to check the accuracy of transcription, with no alterations requested.

4.3.4.2 Participant Observation

During phases 2 and 3, overt observational methods were used to determine relationships between viewpoints from interviews and the actual behaviours of staff. Observations of staff occurred in a range of settings; (i), in the local communities of children and parents participating in a stay at the centre, during the pre- and post-intervention meetings; and (ii), at BHC, during the intake and evaluation interviews, during structured intervention activities (e.g. bike riding, swimming), and
periods of informal interactions and communications (e.g. break times). Observations of staff occurred during the hours of a typical day, 8am-4pm.

Observations provided insights into the practices of staff and phenomena at BHC, and enabled the description and linking of ingredients identified from the interviews to actual practices. Detailed field notes were documented following each observation period, containing descriptions of events, reflections, ideas for further investigation, and preliminary thoughts in relation to the identified active ingredients observed in practice. This allowed exploration, reflection, and reflexive engagement to occur as an iterative process during data collection and analysis. Daily contact with participants meant it was possible to check and confirm the meanings of their behaviour, and adjust or add to the field notes accordingly.

Member checking at the group level occurred in phases 2 and 3. Preliminary results were presented to staff in a workshop format, with their feedback sought to ensure the accuracy of their viewpoints and the researchers’ observations.

4.3.5 Data Analysis

4.3.5.1 Interviews and Focus Groups

NVivo (QSR International Pty. Ltd., 2014) software was used for handling interview data and field notes. Discussions were transcribed verbatim and compared with field notes taken during interview and observation sessions. Transcripts and field notes were read multiple times, and the inductive approach allowed meanings to emerge from the data. Open coding methods and constant comparative coding were used to synthesise the ‘essential elements’ of the intervention identified from interviews. All data was analysed at BHC.

4.3.5.2 Participant Observation

Descriptive and thematic analysis of observation data recorded in the form of field notes occurred away from the clinical field, but onsite at BHC. This involved elaborating upon, completing and refining descriptions of fieldwork experiences, reflecting upon the emotional responses of participants and clients, and examining patterns in behaviour. Observation data and field notes were described within the nine observational dimensions (space, actor, activity, object, act, event, time, goal and feeling). ‘Society’ was added as a tenth dimension, to describe observations relating to
cultural, language and/or social factors specific to Norway. Triangulation of data demonstrated comparable conclusions from each method, strengthening the internal validity of the interpretation. This enabled the development of operational definitions (profiles of practice) to emerge from the active ingredients.

4.3.5.3 ICF-CY LINKAGE

The second process of coding the findings involved using the original data codes as meaning units, and linking these to the ICF-CY according to the process (and recent refinements) described by Cieza et al. These linking rules were devised to enable the linkage of interventions and outcome measures to the ICF-CY. A meaning unit is defined as a specific unit of text, a few words, or a few sentences with a common theme. Meaning units making up each active ingredient were systematically linked to all applicable ICF-CY codes. This involved identifying the meaningful concepts in the condensed meaning units associated with each code. For example the code ‘learning from each other’ was linked to the ICF-CY constructs of ‘acquiring skills’ (d155), and ‘informal relationships with peers’ (d7504). Systematically linking the condensed meaning units to all applicable ICF-CY constructs was completed through a process of consensus between two authors (CW and SG). The authors completed the first third of the linking process together, with 100% agreement. CW completed the remainder of the linking independently, with discussion and review by SG to resolve uncertainties. Sums of identified meaning units and meaningful concepts were calculated, and expressed as percentages linked to ICF-CY components, chapters, and categories. Frequencies of ICF-CY codes making up the active ingredients were analysed to identify trends.

4.3.6 TRUSTWORTHINESS

Several measures were employed to ensure trustworthiness. Triangulation of data collection methods, and triangulation between investigators, enhanced the credibility of the research. Member checking with study participants, the researcher documenting reflections in a journal, and peer debriefing with all investigators in the interpretation of findings, also contributed to this. Employing qualitative methods in tandem and eliciting similar results, enhanced the stability and dependability of study findings, and purposive sampling enhanced transferability. Results were also presented to a consumer-driven steering group in Australia as a method of confirmability.
4.4 RESULTS

4.4.1 PARTICIPANTS

All participants accepted invitations to participate in the study, and all provided informed consent. Thirteen staff from BHC and seven paediatric service providers from various regions of Norway participated in the study. Over the data collection phases, six professionals came to the centre to participate in the three day course the centre runs. A regional consultant from the National Sports Federation (NSF) was also included. The NSF consultant visits every paediatric group in the final week of their stay to assist in linking children and families to sport and leisure opportunities in their local communities. Participants were employed in a broad range of positions with a range of experience, which is reflective of the staff structure at the centre. Demographic information is detailed in Table 4.2.

Table 4.2 Participant demographics

<table>
<thead>
<tr>
<th></th>
<th>BHC staff</th>
<th>LPSP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=13)</td>
<td>(n=7)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td><strong>Years in current</strong></td>
<td>10.2 (2-44)</td>
<td>10.8 (5-14)</td>
</tr>
<tr>
<td>profession**</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Position</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>APA specialist (n=4);</td>
<td>BHC;</td>
<td>Environment facilitator;</td>
</tr>
<tr>
<td>Director of research;</td>
<td>leisure</td>
<td>physiotherapist; NSF consultant*;</td>
</tr>
<tr>
<td>coordinator;</td>
<td>coordinator;</td>
<td>teacher (n=3); teaching assistant.</td>
</tr>
<tr>
<td>occupational therapist;</td>
<td>riding</td>
<td></td>
</tr>
<tr>
<td>physician;</td>
<td>instructor;</td>
<td></td>
</tr>
<tr>
<td>physiotherapist;</td>
<td>social worker;</td>
<td></td>
</tr>
<tr>
<td>riding instructor;</td>
<td>teacher.</td>
<td></td>
</tr>
</tbody>
</table>

LPSP, local paediatric service providers; APA, adapted physical activity; NSF, National Sports Federation; *liaises with every paediatric group at Beitostolen Healthsports Centre (BHC).

4.4.2 IDENTIFICATION OF ACTIVE INGREDIENTS

The data analysis process revealed fourteen active ingredients within the LEM. Active ingredients were categorised according to whether they related to intervention design (n=8), the environment (n=4), and the effect on the individual (n=2). Table 4.3, 4.4 and 4.5 summarise the active ingredients,
the ICF-CY linkage codes relating to the meaningful concepts within each ingredient, and proposed operational definitions.
Table 4.3 Active ingredients: Intervention design

<table>
<thead>
<tr>
<th>Ingredient</th>
<th>ICF-CY linkage code(s)</th>
<th>Example quote</th>
<th>Operational definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group-based</td>
<td>e215, e310, e320, e325, e5800, d155, d7400, d750, d7500, d7502, d7503, d760, d8801, d8803, d9100, d9205, pf, nc, hc-nc</td>
<td>“They want to do activities with other children. That really means something to them. And then you have to focus on pleasure in activities, and not only on health and improvement. So that’s our philosophy, and is also why we do the activities in a group with their peers” – BHC staff member</td>
<td>Children’s groups are made up of 8-10 children from the same municipality. Groups may consist of a range of diagnoses and functional abilities. Ensuring similar ages of children within the group is considered important. Groups facilitate peer-based learning opportunities.</td>
</tr>
<tr>
<td>Activity-based</td>
<td>d1, d2, d155, d1751, d5701, d880, d920, d9201, e1401, e5800, e215, e460, e350, e220, e2100, pf</td>
<td>“They try many different activities [at BHC] so they find one or many they think are good” – BHC staff member</td>
<td>Children participate in a variety of physical activities. Children participate in between 36-72hrs of activity during the intervention. Opportunities exist for unstructured and informal activities to transpire.</td>
</tr>
<tr>
<td>Mutual engagement</td>
<td>e325, e355, e360, e450, e455, e5550, e5551, e5800, e5850, d155, d330-d349, d820, nc</td>
<td>“But this interaction between the local community staff and our staff, that we go to them and they come to us, I think it’s key to the model’s good results...to be sustainable, it has to be equal” – BHC staff member</td>
<td>Engaging in equal relationships with communities to enhance translation and sustainability of physical activity participation into home, school and community environments. There is focus on building partnerships with services in local communities, and empowering service providers to</td>
</tr>
<tr>
<td>Multidisciplinary teams of skilled personnel, including students</td>
<td>e325, e330, e355, e360, e450, e5800, d740, nc</td>
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<td>---------------------------------------------------------------</td>
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<tr>
<td>“We must use what we have learned up here and the experience we have had so we can share it together back in the towns that we come from” – LPSP</td>
<td>translate knowledge within communities.</td>
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<tr>
<td>“There is a lot of overlap. But we need to have one sport instructor and we need one physiotherapist. They each bring something different to the team” – BHC staff member</td>
<td>Rehabilitation teams are made up of skilled physical activity specialists, and other allied health professionals. Students across all allied health disciplines are assigned with a team to complete practicum. Formal communication within the teams occurs daily.</td>
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<tr>
<td>“We really need the students. Because some of the children have very individual needs so we need the students. It would not work as well without them, not at all” – BHC staff member</td>
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<tr>
<td>“Everyone is equal – doctors aren’t seen as superior to anyone else. It’s a level playing field, because everybody’s input is essential” – BHC staff member</td>
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<tr>
<td>Multidisciplinary teams of skilled personnel, including students</td>
<td>e325, e330, e355, e360, e450, e5800, d740, nc</td>
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<tr>
<td>Family-centred</td>
<td>e310, e355, nc</td>
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<tr>
<td>“Because the kids and parents are here to learn activities that they can do at home, so it’s important to have the parents in the activities so they can do it together when they go home” – BHC staff member</td>
<td>Families are incorporated into assessment and intervention. Parent and siblings participate in some (not all) of the activities to ensure that skills and activities acquired during the stay are able to be translated into the family lifestyle. Education is provided to parents on how to make changes to their local environment to facilitate their child’s participation in physical activity.</td>
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<td>“When the family goes home, they often say, ‘Wow we can do so much more than we thought because we came here’. And it’s so important for the families to do something together. Not so that the mother stays at home with the child with cerebral palsy because he can’t go. Here, they realise and they learn that they all can go” – BHC staff member</td>
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<tr>
<td>Goal (child)-directed</td>
<td>d330-d349, pf, nc</td>
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<td>“The most important thing is to involve the kids in the process”</td>
<td>Primary outcome measures are goal-based. Goal setting is collaborative between families and staff, but directed by the child. Children are given the opportunity to express their wants, hopes and goals, to facilitate</td>
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<td>“So it’s a setting where they can talk about it [goals]. The parents also have the chance to say those things too, after the children. Children First! Always” – BHC staff member</td>
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</table>
“We make sure the children’s voices are heard, giving the children the possibility to choose the activities they want, so they have the motivation and the opportunity to be in activities that they want and to train something that is important to them, but in a good way and a fun way” – BHC staff member

Evaluation e5801, e5802, nc

“But the rehabilitation field, especially this part of the field that is focusing on participation, it’s not that easy to say ‘oh we are succeeding’ ” – BHC staff member

“I think the very best part is the follow up this model allows. It means that three months after their stay here, we can go and check how they are going. And if they are having problems, we fix it there and then. We identify the problem and work together to solve it, to make sure what they learnt with us can continue at home” – BHC staff member

“Sending out a questionnaire will give us numbers, but it doesn’t capture the magic” – BHC staff member

Support for stakeholders e3, e310, e340, e355, d7503, pf

“...I feel I can discuss things with anyone. We have a lot of supportive functions in the teams that help us find information if we need it” – BHC staff member

“It’s good to get to know the other professionals working in your community...for us to share ideas, for cooperation, and to ultimately provide the best service” – LPSP

“The parents talk together and create their own supportive environment” – BHC staff member

Assessment is strengths-based, and collaborative with children, families and communities. Focus on identifying barriers and facilitators related to task and environment (pre-, during and post-intervention).

Evaluation of the intervention through formal (outcome measures, interviews, intervention protocol) and informal (feedback, observations in activities, self-evaluation) methods.

Support networks for staff, visiting paediatric service providers, parents, siblings, and children. This may be in the form of training, regular meetings, access to information, connecting like-others, opportunities to share experiences, and ongoing communication post-intervention.
<table>
<thead>
<tr>
<th>Ingredient</th>
<th>ICF-CY linkage code(s)</th>
<th>Example quote</th>
<th>Operational definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘The history is in the walls’</td>
<td>e450, e460</td>
<td>“Erling Stordahl, who started this...he had a unique way of creating and running this Centre and being a leader. So people say the same thing, that he is still living here, that his spirit lives on. We, in some unwritten way, bring that out a little” – BHC staff member</td>
<td>Transformational leadership(^{3}) defines organisational behaviours. This includes building identification with the leader’s vision, challenging staff to think differently, inspiring staff to extraordinary efforts, and building confidence in families and communities.</td>
</tr>
<tr>
<td>‘No limit to possibility’</td>
<td>e450, e430, d7200</td>
<td>“They [the children] say ‘no we can’t’ and we [BHC staff] say ‘yes you can’” – BHC staff member</td>
<td>Staff embody a strengths-based attitude. Focus is on changing the characteristics of the task and/or environment to facilitate participation. This may be in the form of adapting the activity, using assistive or adaptive equipment, individual instruction, and training others in how to facilitate this. Enabling the opportunity to participate is emphasised.</td>
</tr>
<tr>
<td>Across the lifespan</td>
<td>e7503, d7504, e325</td>
<td>“[The children] say they have someone to look up to and see that it works to be an adult also. That you can have a good time and exercise and have friends and everything” – BHC staff member</td>
<td>Adults with disabilities participate in physical activities in separate groups. There is no formal or organised interaction between child and adult groups. Adult and child groups co-exist in daily life during a stay at BHC.</td>
</tr>
</tbody>
</table>
going to have this thing when I grow up. Some children think that this will go away when they are an adult. And adults with wheelchairs teach tricks to the younger ones…they learn from each other” – BHC staff member

“The area we have is quite flat, it has been adapted to the users’ abilities…so it gives opportunities to be active in the [built and natural] environment” – BHC staff member

“A lot of the equipment we have is standard equipment. You find it in everyday school. So when we have those local service providers come up here, a lot of that time is used to show them that they can do a lot with the equipment they already have in school. Of course, we have some special equipment… but most of the time it’s about showing them that it exists” – BHC staff member

“It’s a community they can come to and just relax. A lot of them say that their shoulders go down and they can just be themselves” – BHC staff member

“They often talk about this bubble that they have to burst out of, and go home. So it’s back and forth this institution system…there are some pluses and some minuses” – BHC staff member

The built and natural environment is accessible. Equipment (including adapted or specially designed equipment) is available. Characteristics of the human environment are centred on ‘creating a community’.

pf, personal factor; nc, no code; BHC, Beitostolen Healthsports Centre; LPSP, local paediatric service provider
### Table 4.5 Active ingredients: Effect on the individual

<table>
<thead>
<tr>
<th>Ingredient</th>
<th>ICF-CY linkage code(s)</th>
<th>Example quote</th>
<th>Operational definition</th>
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</thead>
<tbody>
<tr>
<td>Mastery experiences</td>
<td>d155, d750, d8800,</td>
<td>“I see how happy the kids get when they can do something. Because a lot of</td>
<td>Several mechanisms create mastery experiences for children. These include: a variety of activities, individualised goal setting, child’s preference for activities, opportunity for practice, feedback, learning from and with peers, and opportunities for success.</td>
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<td></td>
<td>d8801, d8803, pf</td>
<td>these kids don’t think they can do all of the things other kids can do. But</td>
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<td></td>
<td></td>
<td>when they see they can do it, then their face are like... glowing” – LPSP</td>
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<tr>
<td></td>
<td></td>
<td>“This is not treatment, this is not therapy, this is learning” – BHC staff</td>
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<tr>
<td></td>
<td></td>
<td>member</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>“Everyone gets to achieve something” – BHC staff member</td>
<td></td>
</tr>
<tr>
<td>Friendships</td>
<td>e320, d7500, d9205</td>
<td>“Some of [the children] haven’t got friends or have never had a friend…so</td>
<td>The development of friendships is promoted through the group-based model, and opportunities for unstructured activities. The environment facilitates positive social experiences. Children are from the same communities, enabling the continuation of friendships after the intervention.</td>
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<td></td>
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<td>it’s much more than just swimming, canoeing, and biking” – BHC staff member</td>
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<tr>
<td></td>
<td></td>
<td>“And when they arrive back home, they have their friends who they can do</td>
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<td></td>
<td></td>
<td>their activity with and they’re not the only person with a disability” – BHC</td>
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<td></td>
<td></td>
<td>staff member</td>
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</tbody>
</table>

pf, personal factor; BHC, Beitostolen Healthsports Centre
4.4.3 Concepts from Qualitative Analysis

In total, 113 unique meaning units were identified. A total of 148 meaningful concepts were derived from the meaning units. Of these meaningful concepts, 84% were linked to a total of 53 unique ICF-CY categories and components from the first to the fourth level of the classification. Twenty six categories belonged to the ICF-CY component ‘environment’, and 26 categories belonged to ‘activities and participation’. Nine concepts were not classified on the level of ICF-CY categories but could only be linked to an ICF-CY component in general. These 9 concepts were all linked to the ICF-CY component ‘personal factors’ (pf). No categories related to ‘body function’ or ‘body structures’. The remaining 23 concepts (16%) could not be linked to any ICF-CY component or category (nc).

4.4.3.1 Environment

The greatest contribution of meaningful concepts within the active ingredients were categories within the component of the environment (k=77). All five chapters of the environment were represented in the meaning units of the active ingredients (Table 4.3, 4.4, 4.5). Six of the eight active ingredients relating to intervention design contained codes of categories within the chapter ‘support and relationships’ (k=33). Concepts relating to ‘services, systems and policies’ (k=16) contributed mainly to active ingredients relating to intervention design, and codes within ‘natural and human made changes’ related to active ingredients of the environment. Categories within ‘attitudes’ (k=14) and ‘products and technology’ spanned across both active ingredient categories.

4.4.3.2 Activity and Participation

Eight of the nine chapters of the component ‘activities and participation’ were represented in the meaning units of active ingredients. ‘Interpersonal interactions and relationships’ was the most frequently coded chapter within this component (k=17). ‘Learning and applying knowledge’ and ‘community, social and civic life’ contributed to active ingredients relating to both intervention design and the environment. The remaining chapters made minimal contributions to the active ingredients. The majority of meaningful concepts in the active ingredients category ‘effect on the user’ were linked to categories within this component.

4.4.3.3 Other
Nine concepts were related to the ICF-CY component ‘personal factors’. This is not further specified in categories, but recommended by Ceiza et al. to be coded if the concept is encompassed within the ICF-CY definition.2, 32 In this component, concepts relating to age, gender and outcomes of being a part of a group (e.g. fun), were explored by staff at BHC as mechanisms contributing to intervention outcomes.

Some concepts contained in the meaning units (k=23) could not be linked to any of the ICF-CY components as they were not covered by a specific ICF-CY category (e.g. knowledge translation, time-related aspects, and specific characteristics of the health service). The concept of ‘diagnosis’ was coded as not covered (nc-hc), as recommended by Cieza et al.33 The concept was identified by six participants whilst describing the components of LEM groups participating in the intervention.

The frequency of the total number of ICF-CY categories coded (k=129) within the active ingredients can be seen in Figure 4.2.

![Figure 4.2](image)

**Figure 4.2** Frequency of International Classification of Functioning, Disability and Health: Child and Youth version (ICF:CY) categories, by chapter, represented in the active ingredients.
4.5 DISCUSSION

This study identified the active ingredients of an intervention that enables participation in physical activity for children and youth with a disability. The active ingredients identified by health professionals were organised into three categories; intervention design, the environment, and the effect on the individual. Concepts derived from qualitative analysis and linked to the ICF-CY highlight the role of the environment, and specifically the role of support and relationships, in enabling physical activity participation for children and youth with a disability. This study identified mechanisms that may be considered for future interventions attempting to facilitate involvement in physical activity for children and youth with disabilities.

Eight active ingredients were identified relating to intervention design. Many of the ingredients are novel findings in physical activity and participation literature in paediatric disability; (i) intervention groups are made up of children from the same regional communities, (ii) the type (a variety of structured and unstructured activities) and dosage of intervention, (iii) the engagement of students completing tertiary qualifications across varying fields of allied health, in both the implementation of the intervention and for knowledge translation, and (iv), creating support networks for all stakeholders (children, parents, staff, service providers) involved in the intervention. There is limited literature specifically describing the active ingredients of participation interventions for children with disabilities. Imms et al. recently explored the intervention strategies that appeared effective in attaining the majority of sport and recreation goals for adolescents with a disability. Similar to our intervention, the intervention by Imms et al. was goal-directed (by the child), focused on changing the environment rather than the individual, and there was engagement with communities. For some participants, the intervention was also conducted within a group. Whilst the active ingredients we identified in this study are not ranked in any order of importance, the group-based design was identified by all participants as a crucial component of what happens after the intervention; children and families develop strong social relationships, and create their own support network to encourage ongoing physical activity participation in their local communities.

Four active ingredients were identified in relation to the broader environment in which the intervention is implemented. Two of these ingredients relate specifically to the attitudes and behaviours of staff. Transformational leadership defines organisational behaviours, and staff embody a strength-based perspective that enables every child the opportunity to participate. These ingredients are important to highlight, as the interactive nature of most rehabilitation interventions suggests that therapist behaviour and characteristics are mechanisms for treatment effectiveness.

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This is also emphasised by Alberga et al., who describe ‘lessons learnt’ from involvement in physical activity intervention trials targeting overweight and obese children and adolescents. As well as emphasising a multidisciplinary approach, the recommendations state that ‘choice of fitness trainer matters’. In the context of paediatric disability, as well having sound knowledge and experience in exercise prescription, it is integral that exercise specialists have a comprehensive understanding of the environment (as defined by the ICF-CY) and its relationship to disability and participation. Aspects of the physical environment (e.g. accessibility), as identified by this study and others, are essential considerations to enable physical activity participation across all life settings of a child. Equally as important are the characteristics of the human environment. In addition to the attitudes of staff, creating a community, and the presence of individuals from across the lifespan, were identified in this study to be core components of the environment. The LEM brings people together to explore their connectedness, negotiate their community, and develop physical activity practices. Physical activity interventions that address psychological, social and environmental factors, in addition specific activity goals, may be more effective at developing long-term habits for children and families.

Two ingredients were identified and categorised as ‘effect on the individual’. A proposed mechanism for enabling physical activity participation was a child’s experiences of success and perceptions of their own competence. Self-efficacy (‘a child’s perceived competence and predilection toward physical activity’) has previously been suggested as an intervention target that may be effective at developing lifelong physical activity behaviours for children with disabilities. However, following eight weeks of physical fitness training and behaviour education for youth with cerebral palsy, Slaman et al. reported no changes in self-efficacy after the intervention. This may be because participants in this intervention worked one-on-one with a personal coach. Vicarious experience has previously been identified as the most effective technique to enhance self-efficacy and thus physical activity behaviour. At BHC, children have the opportunity to observe other children and adults with disabilities learn and complete a task, a task that they may not have attempted before, or attempted previously with little success. The segregated group environment facilitates a peer learning approach, and may promote improvements in self-efficacy. Similarly, this segregated environment was proposed to facilitate positive social experiences for children. As children report higher exercise intensities when in the company of peers or close friends, these may be important considerations for engagement in daily physical activity practices that meet the recommended guidelines for children and youth.

Linking the intervention to the ICF-CY verified the substantial role of the environment in enabling participation in physical activity. While all five chapters of the environment were represented in the
meaning units of the active ingredients, the majority contained codes within the chapter ‘support and relationships’. This is consistent with Anaby et al., who demonstrated that all environmental domains in the ICF-CY influenced children’s participation, and social support was the most common facilitator. Of interest, active ingredients that contained meaning units coded within service, systems and policies (e5) also contained codes relating to support and relationships (e3). These meaning units related not only to the health service (e580), but also association and organisational services (e5550) and education and training services (e5850). These codes reflect the cooperation between BHC and community-based health services, leisure and sporting associations, and universities. In practice, ‘relationship-centred care’ is an approach we may need to consider to optimise physical activity participation; a network of relationships not only between children, families and professionals, but also considering peers, mentors, and services in the community.

There were no meaning units that related to codes in the body structures or body function components of the ICF-CY. In the LEM, function is not a primary intervention target, nor considered a barrier; everybody of any ability can participate. This in itself may be a good indication of treatment fidelity, that the staff deliver the intervention as it is intended. While diagnosis is captured for medical records and patient safety, this has no impact on the child’s program. Thus, if a child’s physical activity goal is participation, outcomes of this study should encourage clinicians to look beyond physiological and functional outcomes related to exercise, and focus on skill development and/or aspects of the environment that may facilitate this.

4.5.1 Clinical Implications

Complex interventions are composed of multiple features. Given that participation is a multidimensional construct, and participation is intimately linked with context and the environment, there cannot be one recipe for success. However, understanding the mechanisms that are effective at improving outcomes is a required, and often neglected, step if we are to advance evidence-base practice. Previous physical activity interventions, while effective at improving outcomes at a body functions and structures level, have had little success at changing physical activity behaviours and participation. Of interest, a bike riding intervention with children with Downs Syndrome that embodied many of the active ingredients outlined in this study, demonstrated a significant decrease in time spent in sedentary activity 12 months after training and a reduction in subcutaneous fat in the intervention group. The active ingredients and more practical operational definitions described in this study are provided to encourage others to consider alternative approaches to intervention designs aiming to improve outcomes relating to physical activity participation.
Linking the intervention to the ICF-CY gives this study wider applicability. The ICF-CY represents a globally agreed on structure and common language that can, and should, be used to guide the translation of knowledge into clinical practice.\textsuperscript{2} We encourage the most frequently coded environment and participation-related constructs in this study to be investigated further, as possible variables that may optimise physical activity participation outcomes. Given the global applicability of the ICF-CY, future research may consider the application of these findings in low and middle income countries. The use of a steering group in the development of interview guides, and the exploration of how these active ingredients could be applied in other settings, further denotes the relevance of the outcomes of this study for researchers, clinicians, community organisations, policy makers and children with disabilities and their families.

The limited literature that exists specifically describing the active ingredients of interventions in children with disabilities is largely focused on function.\textsuperscript{50, 51} The identification of the active ingredients of the LEM may encourage more participation-focused outcomes for children and families, which may in turn lead to improved functional outcomes and quality of life.

4.5.2 LIMITATIONS

There are a number of limitations with this study. This research was conducted in one rehabilitation centre in one country, making further investigation into identifying active ingredients of effective interventions in other centres desirable. This study was limited in its access to community-based paediatric service providers. Six professionals visited the centre during the data collection period, which may have limited what we know about community-based providers facilitating participation in physical activity. From a service provision perspective, this does not necessarily imply a negative outcome of the LEM, as children’s participation goals can relate to trying new activities, and/or participation in activities that align with family preferences (rather than goals specific to physical education at school or community sport). Lastly, the ICF-CY linking process includes an element of subjective interpretation about meaningful concepts within an intervention and their corresponding ICF-CY categories. Although two authors completed the process with minimal variation, this is acknowledged as a potential limitation in this study.
4.6 CONCLUSION

To optimise the physical, psychological, and social health benefits of adopting an active lifestyle, identifying strategies that support physical activity participation is paramount. This paper may guide families, exercise specialists, clinicians, investigators, and policy makers, offering ingredients and operational definitions for program design that may assist in enabling physical activity participation in children and adolescents with disabilities. Support and relationships, interpersonal interactions, services in the community, attitudes of health professionals and society, and learning and applying knowledge may be essential considerations for the promotion and sustainability of physical activity participation following interventions.

ACKNOWLEDGEMENTS:

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DECLARATION OF INTEREST

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4.7 REFERENCES


Chapter Five


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The PhD candidate, Claire E Willis, accounted for 85% of the intellectual property associated with the final manuscript (the primary individual involved in the study design, data collection, data analysis, data interpretation, and manuscript preparation and revision). Collectively, the remaining authors contributed 15%. The formatting and references of this chapter follow the guidelines for submission to *BMC Pediatrics*.
FOREWORD

While Chapter Four described the active ingredients of the LEM from professionals involved in the delivery in the intervention, of equal importance is understanding how the intervention works from the perspectives and behaviours of those receiving the intervention. To further our understanding of positive participatory experiences for children and youth with disabilities, a key recommendation from Chapter Two was for future research to identify relationships between components of programs, and understand their influence on outcomes for the child. Chapter Five addresses this, aiming to determine the association between context, mechanisms and child-related outcomes, from the perceptions and behaviours of children and their families participating in the LEM. Outcomes of this chapter highlight implications for future research, clinical practice, and policy, encouraging further testing and utilisation of a theory that explains why specific mechanisms and contexts elicit outcomes that are of importance for children and families.
5.1 ABSTRACT

Background: There is limited evidence describing mechanisms and contexts that may optimise participation outcomes for children and youth with disabilities. This study aimed to describe the association between context, mechanisms and outcome(s) of a physical activity participation intervention to understand what works, in what conditions, and how.

Methods: This study was designed as a Realist Evaluation. Participant recruitment occurred through purposive and theoretical sampling of children and parents participating in the Local Environment Model (LEM) intervention at Beitostolen Healthsports Centre, Norway. Ethnographic methods comprising participant observations, interviews and focus groups were employed over 15 weeks in the field. Data analysis was completed using the context-mechanism-outcome (CMO) framework used in realist evaluation. CMO connections were generated empirically from the data to create a model that indicates how the program activated mechanisms within the program context, to bring about changes in outcomes relating to the child and their participation.

Results: Thirty one children with a range of disabilities (mean age 12y 6m (SD 2y 2m); 18 males) and their parents (n=44; 26 mothers and 18 fathers) participated in the study. Following data synthesis, a refined program theory comprising four interrelated contexts, five mechanisms, and six outcomes, were identified. The mechanisms (choice, fun, friends, specialised health professionals, and time) were activated in a context that was safe, social, learning-based and family-centred, to elicit outcomes across all levels of the International Classification of Functioning, Disability and Health.

Conclusions: The interaction of mechanisms and context as a whole facilitated meaningful outcomes for children and youth with disabilities, and their parents. Whilst optimising participation in physical activity is a primary outcome of the LEM, the refined program theory demonstrated that outcomes of interest to children and parents extended beyond this. Further testing and utilisation of this theory is encouraged.
5.2 INTRODUCTION

Current approaches to rehabilitation of children with disabilities utilise the International Classification of Functioning, Disability and Health: Child and Youth Version (ICF-CY) to assess outcomes, design and evaluate interventions and develop services and policies [1]. To reflect the growing understanding of health and functioning, changes were made to the original World Health Organisation framework to include ‘participation’ as a key element in its guidelines on delivering healthcare [1]. Participation is defined in the ICF-CY as ‘involvement in a life situation’ and is an essential aspect of child health, development, and wellbeing [1]. All children, with and without disabilities, have a need for participation in activities and settings that provide an appropriate level of challenge, social engagement, belonging, and autonomy [2, 3]. However, a significant body of empirical research has demonstrated that children with disabilities experience significant participation restrictions, particularly in participation in physical activity [4]. The importance of physical activity and its promotion for all children and youth is indisputable. While participation in physical activity is influenced by factors at all levels of the ICF [5], evidence of mechanisms that may enable participation for children with disabilities is lacking.

The terms ‘environment’ and ‘context’ are often used interchangeably in rehabilitation literature to refer to factors affecting a child in their surroundings. To clarify, environment is a construct denoting broad external circumstances that may be considered as enablers or barriers to functioning, participation or development [1]; the term ‘context’ refers to the setting for participation (including place, activity, people, and objects), where the person-environment interaction occurs [6]. Current developmental theories and models emphasise the importance of understanding the social context of children and the reciprocal nature of child-environment interactions [7, 8]. Similarly, two recently published reviews of leisure participation describe the central role of social contexts in creating meaningful experiences for children and youth with disabilities [9, 10]. However, there is limited exploration of other aspects of context in participation literature [11]. While the ICF posits that contextual factors play a significant role in determining the extent to which a person is able to participate, the framework does not explain the mechanisms through which context influences participation as an outcome.

While there is a growing body of literature describing evidence-based approaches to improving participation in physical activity in children and youth with disabilities, few interventions have demonstrated change in a child’s participation outcomes [12]. Beitostolen Healthsports Centre (BHC) is a rehabilitation centre in Norway, seeking to enable lifelong activity and participation in local
environments for people with disabilities. Adapted Physical Activity (APA) represents a core theoretical component of the rehabilitation program at BHC [13]. A primary focus of APA and the programs at BHC is to support access to opportunities to be physically active, and develop cooperative service delivery in home, school and community settings [14]. APA has been described as an intersect between therapeutic and pedagogical concepts [15], and is reflected in the model of service delivery at BHC, where a rehabilitation stay is primarily a learning process [16]. Situated learning theory posits that learning is unintentional and embedded in activity, context and culture [17]. ‘Learning’ at BHC denotes becoming involved in new activities, performing new skills, and mastering new understandings. ‘Situated’ describes more than the specific setting in space and time; it infers that learning is a process, shaped by participation and coexistence in social contexts. The BHC program theories describe a context of interaction and learning that provides children with disabilities the opportunity to participate in meaningful physical activities.

In this article, we systematically study how and why the paediatric program at BHC (the Local Environment Model, LEM) works. To identify key combinations of context and mechanisms that trigger outcomes of the LEM, our study is based on a realist evaluation (RE) perspective. Originally developed by sociologists to explore the underlying causal processes by which programs achieve their outcomes [18], RE is has been applied to complex interventions in various health settings [19-21]. RE highlights four key linked concepts for explaining and understanding programs; (i) mechanisms (what it is about programs and interventions that bring about effects), (ii) context (features of the conditions that are relevant to the operation of the program mechanisms), (iii) outcomes (the intended and unintended consequences of programs, resulting from the activation of different mechanisms in contexts), and (iv) context-mechanism-outcome configurations (models indicating how programs activate mechanisms for who and in what conditions, to elicit outcomes) [18]. While the end result of a realist evaluation is a refined set of assumptions (a refined program theory) [18], the explicit connections between concepts are not always clear [19, 22]. In this study, we wanted to uncover the association between context, mechanism and program outcome(s), based on the perceptions and behaviours of the program participants. We aimed to define the mechanisms by which the LEM intervention may facilitate meaningful outcomes for children with disabilities and their parents. Finally, this study aimed to develop a refined program theory describing the relationship between context, mechanisms and outcome(s), to identify the configuration of features that may inform future practice and policy surrounding similar interventions.
5.3 METHODS

5.3.1 DESIGN

Principles of RE [18] underpinned data collection and analysis. Data for RE is typically collected using qualitative approaches [23], and in this study an ethnographic approach was adopted. Ethnographic methods have demonstrated utility in describing the process of change during an intervention, and how and why an intervention ‘works’ [21, 24, 25]. The iterative process of continuous data collection, analysis and reflection employed in ethnography make it possible to identify mechanisms that may enable the improvement and adaptation of interventions and services [26]. In this study, the triangulation of participant observations, interviews and focus groups was utilised to determine the relationship between context, mechanism and outcome during an immersive stay at BHC [18].

Ethics approval for this study was obtained from the Princess Margaret Hospital Human Research Ethics Committee (2013099), The University of Western Australia (RA/4/1/6556), and the Norwegian Regional Committee for Medical and Health Research Ethics, section South-East C (2014/1342-1).

5.3.2 PARTICIPANTS

Purposive and theoretical sampling was used to select participants for this study. In the first phase of data collection, purposive sampling [27] of children and their parents participating in a stay at BHC was undertaken. Children were selected to participate in the study if they were (i) aged between 6-17, and (ii), participating in the LEM intervention at BHC. Parents of children were selected to participate if they were the accompanying guardian and primary caregiver of a child participating in a stay at BHC. Children and parents staying at BHC who met the inclusion criteria were first informed about the study by the Director of Paediatric Teams. Following this, all selected children and parents received their own information sheet describing the study that had been translated into Norwegian. In phase two of data collection, participants were theoretically sampled to elaborate and refine emerging categories relating to how participation in physical activity was enabled at BHC. Theoretical sampling ceased upon reaching theoretical saturation, defined as theoretical completeness in which no new properties of the categories were identified [28].
5.3.3 Description of Intervention

The LEM is an intervention developed by BHC that focuses on enabling families and local communities to facilitate physical activity participation in a child’s home, school and local community. Interventions with children are goal-directed and family-centred, and focus on co-operation, education and resource capacity building in partnership with local communities to facilitate long-term physical activity participation.

Collaboration with local communities occurs one month prior to the intervention at BHC, when representatives from the paediatric teams at the centre travel to the community of the group of families coming to stay, to prepare and engage families and service providers. The main intervention is delivered at BHC, where groups of 8-10 children and their parents stay for 19 days. The children’s stay at BHC is intensive, consisting of physical, social and cultural activities, 2-5hrs a day, six days a week. The intervention is based on the child’s goals (e.g. learning to ski), but also designed to introduce children and their families to new and different physical activities and participation experiences (e.g. rock climbing). Three children’s groups (6-17y), one young adult group (18-30y), and one adult group (>30y) stay at the centre and participate in their specific group program simultaneously. Follow up occurs with children, families and service providers in local communities three months after the stay at BHC.

5.3.4 Data Collection

The first author (CW, independent from BHC) spent a total of 15 weeks at BHC, undertaking data collection over two separate time periods. The first author lived at BHC during 2014 and 2015, and participated in the daily practices of staff, children and families at the Centre. This covered all seasons (summer/autumn and winter/spring), accounting for any intervention-specific differences that occur (e.g. activities, equipment). Proficiency in the Norwegian language aided in the cultural immersion of the researcher.

Ethnographic fieldwork involved the triangulation of semi-structured interviews, focus groups and participant observation, employed over two time points (Figure 5.1).
5.3.4.1 INTERVIEWS AND FOCUS GROUPS

The first author (CW) undertook all interviews. The interviewer was a female PhD Candidate with training in qualitative data collection, with no existing relationship to the participants prior to data collection. Interview guides were developed with the assistance of a consumer-driven steering group comprised of parents of children with disabilities, an adolescent with an acquired brain injury, and professionals working with disabilities in the community. The interview guides were piloted with a manager at BHC to obtain feedback of utility prior to use in data collection. The interview guides covered broad topics for discussion and were revised when new topics were raised during the interviews. Topics discussed and prompts used during the interviews with children and parents at BHC are outlined in Table 5.1.

![Timeline of data collection in weeks.](image-url)
Table 5.1 Key topics and prompts covered in semi-structured interview guides

<table>
<thead>
<tr>
<th>Children</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participation of the child:</td>
<td>Participation of the child in the program</td>
</tr>
<tr>
<td>- Goals for stay</td>
<td>- Goals for stay</td>
</tr>
<tr>
<td>- Initial feelings about BHC</td>
<td>- Child’s initial feelings</td>
</tr>
<tr>
<td>- Overall experience in the program</td>
<td>- Describe child’s experience</td>
</tr>
<tr>
<td>Model of service:</td>
<td>Model of service:</td>
</tr>
<tr>
<td>- Positive and negative aspects</td>
<td>- Participation-related factors</td>
</tr>
<tr>
<td>- Physical activity participation</td>
<td>- Service-related factors</td>
</tr>
<tr>
<td>- Leisure time</td>
<td>- Human environment</td>
</tr>
<tr>
<td>- Human environment</td>
<td>- Physical environment</td>
</tr>
<tr>
<td>- Physical environment</td>
<td>- Similarities/differences to local community</td>
</tr>
<tr>
<td>- Similarities/differences to local community</td>
<td>- Recommendations for improvement</td>
</tr>
<tr>
<td>Effect on child:</td>
<td>Effect of stay on child</td>
</tr>
<tr>
<td>- Perceived changes (of themselves)</td>
<td>- Observed changes (if any)</td>
</tr>
<tr>
<td>- Recommendations for other children</td>
<td></td>
</tr>
<tr>
<td>- What will happen next</td>
<td></td>
</tr>
</tbody>
</table>

BHC, Beitostolen Healthsports Centre

Semi-structured interviews (n=25) and focus groups (n=2) explored the mechanism, context and outcomes of the LEM, based on the perspectives of parents and children participating in the program. Parents participated in in-depth semi-structured interviews (n=18), conducted at a mutually convenient time in a private meeting room at BHC. Norway has very high proficiency in English [29], thus participants were offered the choice to conduct interviews in Norwegian (n=3) or English (n=15). As Norwegian was not the primary language of the first author, a translator (MM) was present during these interviews to ensure accurate interpretation of questions asked by the interviewer (CW) and answers from the interviewee. Interviews duration with parents ranged from 45-75 minutes.

Two focus groups with children (n=11) were conducted in phase 1, and each went for 45 minutes. Semi-structured interviews were conducted with an additional seven children in phases 1 and 2. Depending on the preferences of the children, these were conducted individually (n=2), or with a parent present (n=5). Interviews conducted individually were done so in English, and were 60 minutes in duration. For interviews where a parent was present, the parent acted as a translator to verify interpretations of the child’s responses by the interviewer. All parent supported interviews went for 30 minutes.

The first author transcribed each interview and focus group from the recordings verbatim. Norwegian interviews were transcribed in Norwegian and translated to English by the first author. Whilst
researchers who also act as translators are rare, this method enhances the validity of interpretations as it allows close attention to cross cultural meanings and interpretations [30]. English translations were then back-translated by the translator that was present in the interviews (MM). Credibility was enhanced by the researcher documenting reflections in a journal following the interviews and demonstrating an audit trail of the research methods [27]. Approximately half of the interview participants had the opportunity to review their transcribed interview, and made no changes.

5.3.4.2 PARTICIPANT OBSERVATION

During phases 2 and 3, overt observational methods were used to determine relationships between viewpoints from interviews and the actual behaviours of children and parents [31]. Observations of children and parents occurred in a range of settings at BHC; throughout intake and evaluation interviews, in structured intervention activities (e.g. bike riding, swimming), and during periods of informal interactions and communications (e.g. break times). Conversational interviews with children and parents also occurred spontaneously in these settings. Observations of children and parents occurred during the hours of their typical day, 8am-8pm. Non-participants (i.e. individuals aged 18 years or older and/or families participating in an alternative program) were present during the observation period, and while aware of the research project being undertaken, no record of their actions, behaviours or discussions were documented.

Observations provided insights into the phenomena experienced by children and parents at BHC, and enabled the description and linking of mechanisms and outcomes identified from the interviews specific to their proposed context. Detailed field notes were documented immediately following each observation period, containing descriptions of events, conversations, reflections, ideas for further investigation, and preliminary thoughts in relation to the identified mechanisms observed in practice. This allowed exploration, reflection, and reflexive engagement to occur as an iterative process during data collection and analysis [26]. Daily contact with participants meant it was possible to check and confirm the meanings of their behaviour, and adjust or add to the field notes accordingly [32].

5.3.5 DATA ANALYSIS

5.3.5.1 INTERVIEWS AND FOCUS GROUPS

NVivo (QSR International Pty. Ltd., 2014) software was used for handling interview data and field notes. Discussions were transcribed verbatim and compared with field notes taken during interview
and observation sessions. Transcripts were analysed using direct content analysis [33] and guided by the context-mechanism-outcome (CMO) framework used in RE. A phrase was coded as context if it described the circumstances that formed the setting for an event and/or experience. Mechanisms were components of the program that were proposed to create outcomes. A phrase was coded as an outcome if it described the impact of the program on the child [23]. After applying the CMO coding framework, data within each domain were reviewed to merge similar codes and synthesise the mechanisms, context and outcome themes of the intervention. The first author coded all interviews, and a second author (SG) reviewed and checked the coding with no disagreement.

5.3.5.2 Participant Observation

Descriptive and thematic analysis of observation data recorded in the form of field notes occurred away from the clinical field, but onsite at BHC. This involved elaborating upon, completing and refining descriptions of fieldwork experiences, reflecting upon the emotional responses of children and parents, and examining patterns in behaviour. Observation data was coded in the same manner as the interview transcripts, to synthesise observed mechanisms, context and outcomes. Mechanisms and outcomes identified in interviews also emerged from the contextual descriptions and observed participant behaviours. The triangulation of data demonstrated comparable conclusions from each method, strengthening the internal validity of the interpretation [34].

5.3.5.3 Realist Evaluation

The intent of RE is to develop a set of possible relationships between the context, the intervention mechanisms, and the outcomes [23]. In this study, we wanted to identify the connections participants made between the features of the context, the program elements and the outcomes they experience. In addition to individual codes assigned in the qualitative coding (a discrete C, M or O), we focused on identifying strings of CMOs linkages (CO, MO, CM, CMO) within each code [23]. Generating the CMO connections empirically from the data allowed us to explore the different constellations of specific contexts and outcomes that participants themselves identified. Common links and consistent patterns between context, mechanisms, and outcomes across the data were identified to generate a CMOc (context-mechanism-outcome configuration). The CMOc is a model that indicates how the program at BHC activated mechanisms amongst children with disabilities within the program context, to bring about changes in outcomes relating to the child and their participation.

5.3.6 Trustworthiness
All four aspects of trustworthiness were addressed to ensure the overall rigour of the research. Triangulation of data sources, prolonged engagement at the site, and persistent observation strengthened the credibility of interpretations [34]. The sampling strategies and detailed descriptions of participants (Table 5.2) enhanced the transferability of the data. Dependability was address by the documentation of researcher reflections and demonstrating an audit trail of the research methods [27]. Results were presented to the steering group in Australia as a method of confirmability [27].

5.4 RESULTS

5.4.1 PARTICIPANTS

All participants (n=75) accepted invitations to participate in the study, and all provided informed consent (and assent). Thirty one children and their parents (n=44) participated in the study. Children had a mean age of 12y 6m (SD 2y 2m) and had a range of physical and intellectual disabilities. Of the 44 parents who participated in the study, 13 were parent dyads. A total of sixteen children and eighteen parents participated in semi-structured interviews or focus groups. Demographic information of all participants is detailed in Table 5.2.
Table 5.2 Participant demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Category</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>Children</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>Parents</td>
<td>44</td>
</tr>
<tr>
<td>Parent relationship to child</td>
<td>Mothers</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Fathers</td>
<td>18</td>
</tr>
<tr>
<td>Characteristics of children</td>
<td>Age, y:m (SD)</td>
<td>12:6 (2:2)</td>
</tr>
<tr>
<td></td>
<td>Age range, y</td>
<td>6-17</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
</tr>
<tr>
<td>Child's primary health condition</td>
<td>Cerebral Palsy</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>GMFCS I/II/III/IV/V</td>
<td>5/4/1/1/1</td>
</tr>
<tr>
<td></td>
<td>Acquired brain injury</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Intellectual disability*</td>
<td>17</td>
</tr>
<tr>
<td>Number of stays at BHC (n)</td>
<td>1st</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>n&gt;1</td>
<td>11</td>
</tr>
<tr>
<td>Interview participants</td>
<td>Children</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Parents</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Mothers</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Fathers</td>
<td>2</td>
</tr>
</tbody>
</table>

GMFCS, Gross Motor Function Classification System; SD, standard deviation; BHC, Beitostolen Healthsports Centre. *Including Downs Syndrome, Fragile-X syndrome, and craniosynostosis.

5.4.2 CONTEXT, MECHANISM, AND OUTCOME

Data analysis revealed a clear relationship between context, mechanisms and outcomes. The context, mechanisms and outcomes were comprised of sub codes as in a typical qualitative analysis. The study generated 39 context codes, 24 mechanism codes and 27 outcome codes. Thematic analysis revealed 4 context themes, 5 mechanisms, and 6 outcomes. These categories form the sub-headings of our results below. Results focus firstly on the context that describes the conditions relevant to the operation of mechanisms; secondly, the mechanisms that were operationalised within the context and produced outcomes; and lastly, the outcomes that resulted from the mechanisms and context. Context (C), mechanism (M), and outcome (O) variables are indicated within the quotes. Quotes are accompanied by an annotation that indicates whether the quote is from a parent (perspectives did not differ between mothers and fathers) or a child. Quotes from children are accompanied by their age, and whether they have a physical disability (PD) or intellectual disability (ID). Further examples of strings of CMO linkages can be seen in Table 5.3.
5.4.2.1 Context

Context comprised four interrelated conditions; safe, learning, social, and family. Both children and parents described all four contextual conditions.

C1. Safe:

‘Safe’ refers to the emotional safety that was necessary for a child to reveal their needs and feelings, explore new environments and experiences, and for social confidence to develop. Secure human relationships were the primary mechanism attributed to creating feelings of safety:

“The most important thing is the people. He [child, 9y, ID] has become very attached to [staff member] (M4) and the other boys in the group (M3). It’s the people that help him feel secure and safe here (C1)” – parent

This safe context was a setting children felt they could explore their limits, take on challenges, and try new things. For children, feeling safe provided them a freedom to take risks and make errors, without the fear or need for self-protection of potential social consequences. Feeling safe facilitated learning:

“I feel like I can try new things because I feel safe here (C1)” – child, 17, ID

C2. Learning

Learning describes a context that enabled children to acquire new (or reinforce existing) skills, behaviours and preferences, and to master new understandings. This context was shaped by the range of novel activities that constitute the intervention, and was a large contributor to a child’s engagement in the program.

“I have learnt to try new things (C2)…Here, everyone can find something they love to do (M2)” – child, 9, PD

The context of learning referred not only to activity exposure and acquisition, but also to knowledge gained from being around others. Children described how ‘meeting new people and seeing people with different disabilities’ meant they ‘learnt a lot about new things’. Parents explained that learning in a social context was important for their children:

“I think it’s really important that our kids learn to think about others (C2). That they are not the only one to be taken care of, that others also need to be heard
and that sometimes they have to wait... To see that there are other people with other needs (C3)” – parent

C3. SOCIAL

The social context refers to other individuals with disabilities that children interact with throughout the duration of the program. Children described this as a place where you could ‘make friends, and just be together’. Being together in a social group was often described by parents as ‘the best part’ of the program for their children. This was considered a motivational tool for engaging children in physical activity, particularly for children with intellectual disabilities where ‘everyone is motivating each other’. For others, this context was meaningful just for ‘the opportunity to be around other people’. Parents frequently described the social context as an uplifting change to the loneliness and isolation that children experienced in other social settings:

“The kids in the street, they don’t want to play with her. She’s different, and she’s slower, and she can’t do what they do. You see how much [child, 12y, PD] just fits in here (C3)...she absolutely loves it. She wants to stay for another four weeks!” – parent

Being around people with disabilities fostered self-reflection in children of all ages, with many describing this context as a place where a child ‘felt like I could be myself’. Some parents felt this was a learning experience that would shape their children’s lives:

“When we came, [child, 9y, PD] said, ‘What am I doing here? There are so many people that are different (C3)’. And we had to have a talk about being different. Before, she thought that she wouldn’t have cerebral palsy when she grows up. And now she understands (C2), ‘Maybe I [will] have [CP] my whole life’ ” – parent

C4. FAMILY

Family, notably primary caregivers, were also considered in the circumstances that form the context of the program. Initially, children were happy to explore the new environment (BHC) as long as they were in the presence of secure attachment (caregiver). Children became anxious in the presence of novelty (e.g. activity) when their caregiver was absent:

‘The first activity this morning was ‘activity bingo’. This wasn’t an activity that parents were invited to participate in. However, [child, 11y, ID] refused to let go of his Mum’s hand (C4). [Child’s Mum] stayed with us for the warm up, but was
firm saying she would not join [the activity]. [Child] looked absolutely terrified, but [staff member] (M4) convinced him to join him and [friend] in the activity (C2)’ – CW observation

As relationships between staff and children developed in the engaging environments, children’s sense of security deepened. For younger children, participating without the presence of parents often was a novel experience, one they were proud of, generating a new sense of independence they wanted to further explore:

“Now I can stay without Mum (C4) in the swimming pool, and in the big hall and in the small gym and on the horse (O1, O4). And today is the first time Mum won’t be with me for the push bikes” – child, 9, PD

Children generally enjoyed having their parent(s) with them during the program, describing the experience as “very fun” (O3). Only one child (male, 15, ID) disagreed, describing his mother as “embarrassing”.

5.4.2.2 MECHANISMS

Five mechanisms were identified by children and parents:

5.4.2.2a CHILD IDENTIFIED

One mechanism was identified solely by children as an important factor for inducing program outcomes.

M1. CHOICE

Choice was identified by children as a mechanism that facilitated engagement and enjoyment in physical activity, and aspirations for future participation. While a child’s program at BHC is based on their participation goals, they are exposed to a variety of physical activities. Choice and voice during goal setting, within the activity program, and outside of formal activities, was an essential element for a child’s engagement and enjoyment. As one adolescent girl described,

“I have been swimming a lot and I went to the disco! (C2). But I don’t do shooting. I do some of the activities but only the ones I want to (M1)” – child, 16, ID
This experience of both choice and variety was helpful for some children in exploring their activity preferences. The operationalisation of choice in the learning context encouraged children to consider their ongoing participation in physical activity and future participation opportunities.

“We have tried different things here (C2), so we have more to choose from when we go home (M1). Now I have ideas of the things I want to do when I go home (O2)” – child, 17, ID

5.4.2.2 CHILD AND PARENT IDENTIFIED

Three mechanisms were identified by both children and parents as factors that induced program outcomes.

M2. Fun

Fun was identified by children as a mechanism that created enjoyment in physical activity, and motivated children to achieve their goals. If the activity was not fun, this outcome was not achieved. Children often explained this in relation to both the learning and social context:

“I hate swimming at school. It’s not something I love. But the training [swimming] here with everyone (C2, C3) is so fun. At school it is boring” – child, 9y, PD

Parents believed in the inherent value of activities being fun, a mechanism essential for motivation and progression. Parents frequently described fun as a covert mechanism to achieving body function-based outcomes that were meaningful to them:

“It [rock climbing] is so good for his [child, 6y, PD] arms. It’s strengthening his arms a lot and it’s a good way of building his self-confidence because he will manage to climb different kinds of routes (O1, O6). So it’s not only fun (M2), it’s good for him also (O6). Like all of the activities here.

M3. Friends

Having friends was a unique variable, in that parents and children identified it both a mechanism and an outcome. Both parents and children described friends as the reason for such positive experiences in the program. These were often so meaningful that children aspired for these relationships and positive experiences to be a permanent part of their future:
“The best would be to live with my friends [from BHC] (M3) with all of our happy dogs and be happy all together (O2)” – child, 16, ID

Friends were a salient feature of outcomes of achievement and enjoyment in physical activity. They provided motivation that enabled children to persevere when activities were ‘hard’ or ‘uncomfortable’. Sharing these achievements with their friends was also highly meaningful to children:

‘He [child, 14, PD] was the last to finish the cycle course, and all of his friends were cheering him on, helping him to finish (M3). When he crossed the finish line, he had the biggest smile on his face. He was so proud, and so thrilled to see that everyone was cheering for him. He punched two hands in the air, threw his head back, and said ‘yes’! (O1) – CW Observation

M4. SPECIALISED HEALTH PROFESSIONALS

Staff were a mechanism that influenced all outcomes. Children described staff as ‘the world’s best’, explaining how staff were crucial to enabling them to achieve their goals, and perform and participate in activities independently:

“Because the people who work here (M4), they help you and tell you how you can do it on your own (O4)! So it makes it very easy and very fun to do things here (O5)” – child, 16y, PD

The abilities of the health professionals to adapt physical activities to the needs of each individual did not go unnoticed by children or parents. For parents, having specialised staff ‘is so important’ and made it ‘easier to let go’ during the program. Parents perceived staff as providing a highly individualised model of service, contributing to creating a safe learning environment:

“Here, the whole team (M4) work together and everyone knows my daughter, and they know when to push [child, 16y, ID] and they know how to motivate her to try new things. They introduce her to new things (C2). Often, she really wants to do [an activity] but she is scared. But the staff here keep trying and break things down into small steps. So it’s a safe place to do things (C1), because the staff are genuinely interested in the child and they know the child so well. They try and try and try, with whatever each child needs. They are fantastic. Nothing is a problem for them” – parent
5.4.2.2c Parent Identified

One mechanism was identified only by parents as being a factor that induced program outcomes.

M5. Time

Time was discussed by parents as mechanism that facilitated the evolvem
ment of context. Time was what children needed to ‘feel secure and to feel safe’. Time facilitated learning, and allowed children to attempt activities at their own pace. Time was a requirement for group development, which formed the basis for peer relationships:

“For her [child, 12y, PD], making friends (O3) is something that takes time
(M5)” – parent

Time was an important mechanism for all outcomes, ‘important because then children do not feel stressed with change’. Time was discussed in relation to changes in body function, as a mechanism that enabled children ‘to focus on how to use their bodies’. Time was described as crucial for mastery of skills, achievement of goals and independence in social and activity settings. Importantly, time enabled children to enjoy the participation experience:

“She [child] is really afraid of horses. But now for the first time, they have been talking to the horses every day. And the other day, she was sitting on a horse. And she was so proud (O1). Smiling and laughing and waving (O5)! But my goodness, before she was so afraid. And now [with time] (M5), she is perfectly fine” – parent

5.4.2.3 Outcomes

Six program outcomes were identified by children and parents:

5.4.2.3a Child Identified

Two program outcomes were identified solely by children.

O1. Achievement

Achievement refers to the mastery experiences that children experienced during the program, an outcome that resulted from the attainment of participation goals, or successful attempts at novel activities. Achievement was a highly meaningful outcome for children:
“It [achieving participation goal] is such a big thing for me. I cannot tell you how much in words. It’s so big, I cannot tell you how big it is” – child, 16y, PD

**02. Aspiration**

Aspiration describes the ambition that children acquired during the program. Children were able to recognise and understand their capabilities, which encouraged them to consider goals for the future. Aspirations related to building on their physical activity participation achievements:

“Now I want to learn how to balance [on the bike] by myself” – child, 9y, PD

Some children looked further into the future, and applied their skills and participation experiences to employment aspirations:

“When I grow up, I want to be a professional footballer” – child, 10y, PD

**5.4.2.3b Child and Parent Identified**

Three program outcomes were identified by both children and parents.

**03. Friends**

Friendships were perceived as a momentous outcome of the program for both children and parents. Children typically explained the outcome of friends as a quantity, i.e. ‘now I have many friends’, and that ‘the best part [of BHC] was making my first friends’. The significance of these (new and growing) friendships was reinforced by parents, particularly for those whose children had participated in multiple stays at the Centre:

“I think that the best thing out of it the first time was all of those friendships. And that they have stayed together ever since” – parent

The data revealed that it was context that facilitated friendship development, rather than specific mechanisms. Children and parents described friends as an outcome of the safe, social context:

“[At home] he [child, 11, ID] has no close friends. Just because he is different. Here, he feels safe (C1). He is close to everybody (C3). The boys are a ‘pack’!”
– Parent

**04. Independence**
Parents described independence as an outcome that occurred as a result of the time spent in the context of the program. Independence in physical activity was an important facilitator to a child’s ongoing participation:

“When we take a bike trip with my kids, I always have to stop and help him. And his bike, it’s so heavy with all of its chairs and wheels, and I have to help him and my bike over the road. But now he’s going to be able to do it himself” – parent

Children described this outcome in terms of being able to manage skills and activity participation without the assistance of others:

“I am more independent. I get help if I need it but now I can do it myself” – child, 11y, ID

O5. ENJOYMENT IN PHYSICAL ACTIVITY

Parents described their initial desires in the program for their child to ‘enjoy being active’ and ‘feel motivated to participate in physical activity’. Parents wholeheartedly believed that their child’s experience at BHC had enabled them to have positive experiences in physical activity participation. This was generally described in relation to context:

“…we were up in the mountain. That was so much fun (O5)! And when we got there, I forgot that she [child, 16y, ID] was so afraid of snow. She is afraid of just walking in the snow. She always cries a little. And this time, after having tried the snowshoes [at BHC] (C2), she was fine. Absolutely no problem. She forgot that she was afraid of the snow and enjoyed the walk (O5)” – parent

Children described physical activity participation at BHC as highly enjoyable and ‘very fun’, with no children inferring any negative feelings towards their experience. Children ‘would like to stay for longer’, and if given the opportunity, would let other children know that:

“When you come here, you just have fun. That is very important. And you are active. They are the two most important things to know. Being active is fun.” – child, 16y, PD.

5.4.2.3c PARENT IDENTIFIED

One program outcome was identified only by parents:

O6. BODY FUNCTION AND ACTIVITY-RELATED IMPROVEMENTS
While not the primary motivation for participating in the program, parents expressed the importance of the health and functional benefits gained from the physical activities at BHC. In addition to perceived physiological changes, those related to a child’s personal disposition were an outcome observed by most parents:

“She [child, 16y, ID] has really benefitted from all of the physical activity. She can last for longer in activities, and she is happier and more confident in herself and what she can do (O6)” – parent

A child’s skill development, both activity-based and in a social context, was a meaningful outcome for parents. Parents not only observed these improvements, but also commented on how quickly they were attained:

“In her [child, 12y, PD] social confidence, in her balance...at home this is rare but here it’s happened so quickly. It’s amazing how easy it comes. So quick. And I thought that this is not going to happen, but it did, and so quick!” – parent

Children did not make reference to perceived health benefits. However, one adolescent (GMFCS V) commented on his participation in a gym program:

“When I came here I trained to be a small boy, and not be a fat boy. But when I was here and when I talked to people (C3), they helped me to know that it’s not good to think in this way. It’s good to think that when you train, you will be stronger (O6). And you will be able to help your father and you will be able to help yourself (O4)” – child, 16y, PD

5.4.3 CONTEXT-MECHANISM-OUTCOME CONFIGURATION

As the raw data within the thematic results infer, mechanisms, context and outcomes were interrelated, as described by children, parents and the researcher (Table 5.3). This led to the development of a CMOc from the LEM (Fig. 5.2). This generative causality model provides an account of why the outcomes transpired as they did. Thus, the causal explanation is not a matter of a singular mechanism (M), or a combination of mechanisms (M1.M2) asserting influence on an outcome (O). Rather it is the association as a whole that is explained. Accordingly, Figure 5.2 removes the causal arrow and replaces it with the dumbbell shape, representing the tie or link between the set of variables (mechanism and outcome, within context), and explaining the consistency between context, mechanisms and outcomes [18].
Figure 5.2 Context-Mechanism-Outcome configuration of the Local Environment Model
Table 5.3 Examples of Context-Mechanism-Outcome linkages within themes

<table>
<thead>
<tr>
<th>Context-mechanism-outcome configuration</th>
<th>Sample quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Context:</strong></td>
<td></td>
</tr>
<tr>
<td>C1. Safe</td>
<td>“He [child, 11y] has problems with anxiety. He normally gets very withdrawn and stressed in new situations, at times when he doesn’t feel safe, you know. But here, I have barely seen him like that. The boys have become very good friends (M3), they do everything together. And that helps him feel safe (C1)” – parent</td>
</tr>
<tr>
<td>C2. Learning</td>
<td>“I will remind her of the things she has learnt [at BHC]…and lead her back here (C2), to remind her that she can actually do it. That’s part of the whole thing I think. She learns what to do here so we can do it when we go home” – parent</td>
</tr>
<tr>
<td>C3. Social</td>
<td>“With the group, she [child, 16y] sees that the others can do things (C2). Everybody is together, so she’s not the only one working out (C3)” – parent</td>
</tr>
<tr>
<td>C4. Family</td>
<td>“He [child, 11y] doesn’t want me there anymore [in activities] (C2, C3). He feels safe here (C1), so he wants me to leave (O4)” – parent</td>
</tr>
<tr>
<td><strong>Mechanism:</strong></td>
<td></td>
</tr>
<tr>
<td>M1. Choice</td>
<td>“When I got here (C3), they [staff] said to me, you can choose your activities…and most of the activities I chose (M1), I have been able to try in my time here. Some of them were very difficult but they were very fun (O5)” – child, 16, PD</td>
</tr>
<tr>
<td>M2. Fun</td>
<td>“It [horse riding] is so fun and it’s fast (O5). It’s hard, but it’s fun (M2). So I like to keep trying at it (O5)” - child, 17y, ID</td>
</tr>
<tr>
<td>M3. Friends</td>
<td>We live in a small place, and he doesn’t have many friends at home. But [child] has made friends (M3) here with all the boys (C3). And so he has had so much fun (O5) – parent</td>
</tr>
<tr>
<td>M4. Specialised health professionals</td>
<td>“She [staff member] is a very special person for me and my family, because she did so much for me (M4). I am so proud of what I can do now (O1)” – child, 16y, PD</td>
</tr>
</tbody>
</table>
M5. Time

“And they can try many things that would be very difficult to try for the first time at home (C2). You can try to ride a horse, you can try an electric car...everything. You are not just come for one day with many strangers and then having to try immediately...there is time (M5). And maybe it’s very scary the first time and the second that’s ok because there is time. You have time (M5) to learn (O1)” – parent

Outcome:

O1. Achievement

“So now I can do it [participation goal](O1)! It’s very exciting and I am so happy because I never...because I could never do that before. It was the first time” – child, 16y, PD

O2. Aspiration

“After my last stay, I have started horse-riding at home. Now I want to do competitions (O2)” – child, 17y, ID

O3. Friends

“Now [at BHC] I have this friend (O3), his name is [child] and he is 16y and he has the same handicap as me (C3). So we have kind of the same problems and we have the same interests. So he will come home to the same place as me. And I said if you come and visit me I will show you the football place. Because now we both love football a lot (O5)” – child, 16, PD

O4. Independence

“She [child, 17y, ID] becomes more independent (O4) after the time (M5) we have spent here (C1, C2, C3). You can see the difference every time” – parent

O5. Enjoyment in physical activity

“I have seen him [child, 14y, ID] do everything here (C2), and now you can see that he enjoys being active and doing all of the activities (O5)” – parent

O6. Body function and activity level outcomes

“This is so great. His [child, 9y, PD] physiotherapist at home has been saying for ages that roller-skating would be so good for his balance (O6), but we just haven’t been able to try it. It’s so fantastic that you [staff] (M4) thought to try that here today” – parent/CW observation

PD, physical disability; ID, intellectual disability; CW, first author.
5.5 DISCUSSION

This study demonstrated a clear and consistent relationship between context, mechanisms and outcomes of the LEM intervention to generate a CMOc model and refined program theory. This theory integrates mechanisms and context to predict and explain outcome patterns for children and youth with disabilities during a physical activity intervention. This study identified five mechanisms (choice, fun, friends, specialised health professionals, and time) that facilitate meaningful outcomes for children with disabilities and their parents. We demonstrate that the LEM intervention activated these mechanisms amongst children with disabilities in a context that was safe, social, learning-based and family-centred, to elicit outcomes across all levels of the ICF. Of importance, this theory describes that it is not a matter of a singular mechanism (or even a combination of mechanisms) asserting influence on one outcome, but the interaction of mechanisms and context as a whole that facilitates outcomes.

Whilst optimising participation in physical activity is a primary outcome of the LEM [35], the findings of this study demonstrate that outcomes for children and parents extended beyond this. Mastery experiences, independence in participation, authentic relationships, and hopes for the future were all identified by children as equally meaningful outcomes of the program. Furthermore, parents perceived the participation-based intervention to elicit outcomes at the level of body functions and activity. This is a novel finding in paediatric disability literature, with implications for rehabilitation interventions attempting to improve outcomes at a body functions and activity level. This raises the question; can participation interventions, that are highly engaging for children over sustained time periods [36], contribute to improvements in impairments and activity limitations? Emerging evidence suggests that long-term involvement in exercise may improve neuromuscular characteristics and functional capacity of people with cerebral palsy [37]. In typically developing children, those who regularly participated in sport over three years displayed better motor outcomes than children who only partially participated, or did not participate in sport at all [38]. In these studies (and ours), participants were not involved in interventions specifically designed to enhance body function or activity outcomes; rather, they were participating in physical activity and exercise pursuits that were intrinsically motivating to them. The outcomes of our exploratory research may warrant further investigation of this hypothesis for children and youth with disabilities.

Our findings support the notion that effective interventions are dependent on contextual interdependencies. The interrelatedness of safe, social, learning and family contexts was required for the operation of the program mechanisms. While the role of family and social contexts in enabling
participation is increasingly being documented [10], the concept of ‘safe’ learning contexts is relatively unexplored. While many articles centre on environments or strategies that ensure physical safety (of which is of utmost importance) [39, 40], our results explore the idea of a central context that is perceived by children and parents to be emotionally safe. In this study, secure human relationships were the primary mechanism attributed to creating feelings of safety. Initially, this security was provided by a child’s family, which facilitated a child’s early engagement in the learning context. As a child’s sense of security deepened, facilitated by developing relationships with staff and other children, the attachment to caregivers dissipated and children actively engaged in the learning and social contexts without fear or need for self-protection. In sociology, this experience of emotional safety is termed ‘membership’, proposed to be created by being a member of an integrated group that has boundaries and emotional security [41]. The results of this study suggest that affirming membership of a group supported a child’s inclusion through shared and emotional connections. Reconstructing ‘safe’ contexts may be a primary consideration for interventions aiming to engage children in physical activity pursuits. Furthermore, social and family contexts that facilitate the development of secure relationships may assist in ongoing participation in physical activity after the intervention has ceased.

Five mechanisms were operationalised by the safe, social, learning, and family context of the LEM. While choice, friends, and fun have previously been proposed as mechanisms that may facilitate participation in physical activity [10], there is limited understanding of the role of health professionals in achieving this outcome. In this study, having access to specialised health professionals that provided an individualised service and were highly competent in facilitating physical activity participation was described by both children and parents as crucial to the outcomes of the program, and beyond. Despite the multidisciplinary nature of the teams, behaviours of health professionals at BHC strongly aligned with the values of APA specialists; i.e., an abilities-based approach to professional practice where the focus is on the person in a learning situation (rather than in a treatment situation) [42], adopting person-centeredness, operating with openness (inclusion in all types of physical activity opportunities), creating compatibility (the interaction between the person, environment, activity and participation) [43], and fostering empowerment and self-determination of individuals [13]. Results from this study support that health professionals are important mechanisms for intervention effectiveness [44], but also highlight the central role of skilled professionals in enabling a child’s participation in physical activity.
5.5.1 IMPLICATIONS FOR POLICY AND PRACTICE

Outcomes of this RE offer particular advantages for practice and policy. As realist approaches acknowledge and accommodate the ‘messiness’ of real-world interventions by asking different questions (not just ‘whether’ but ‘how’ and ‘for whom’), they can inform the tailoring of interventions and policy to particular purposes (such as optimising participation in physical activity), to specific target groups, and in particular sets of circumstances [18]. This is relevant when considering ‘time’, identified by parents as a mechanism that both facilitated the evolvement of context, and elicited outcomes. For both families and clinicians, time is a resource when it is available; and its absence often redefines time as a constraint. While intensive intervention models (whereby time is also an active ingredient) have demonstrated effectiveness in improving clinical outcomes in a research setting [45, 46], a number of barriers exist surrounding their implementation into clinical practice. Results from this study suggest that an intervention model that incorporates ‘time’ as an active ingredient may be effective for improving participation outcomes; not necessarily because it allows for greater intervention dosage, but for its role in creating safe contexts, facilitating learning, and fostering peer relationships, which in turn lead to outcomes. These results may be of particular value for policy makers and funding bodies; an explanation of why a program mechanism works to elicit outcomes that are of importance for children, families, and professionals may advance the implementation of research into policy.

An important principle of realism research is that, in contrast to other research paradigms, the ‘causes’ of outcomes are not simple nor deterministic [47]. Practitioners should therefore be aware that the mechanisms of choice, fun, friends, specialised staff and time, will not cause the perceived outcomes, but they may make these outcomes more likely, if operationalised in the right contexts. Interestingly, the findings of this research were independent of age, gender, and disability of children, which may encourage its application across a range of clinical settings. The mechanisms, contexts and outcomes described in this study incorporate the essence of ‘the F-words in childhood disability’ (function, fitness, friends, family, fun and future) [48], and present a novel approach to how this widely adopted framework is incorporated into clinical practice. In highlighting the bidirectional nature of the ICF, these authors similarly encourage the reader to imagine how a child’s participation and engagement in physical activity may have an important impact on outcomes across all domains [48]. While RE attempts to pinpoint the configuration of features needed to replicate an intervention program, we encourage the application of findings from this study to be considered in parallel with broader frameworks to enhance its transferability.
5.5.2 LIMITATIONS

There are a number of limitations with this research. Ethnography is a time intensive methodology, and not all interviews were able to be transcribed in the time that parents and children were at the centre. As such, we were not able to include a complete member checking process, although 50% of participants were reached. Additionally, there were a greater number of female caregivers involved in the study, which may have impacted our understanding of the program with limited perspectives from male caregivers. However, this sample was reflective of the demographics of caregivers staying at BHC, as were those of the children. Finally, the results of an RE are conditioned by the nature of the programs they investigate, meaning that these findings are provisional. While we have developed a theory about what works for whom in what context, we encourage future investigation and testing of our hypotheses.

5.6 CONCLUSION

This study demonstrates that it is the interaction of mechanisms and context as a whole that facilitates outcomes for children and youth with disabilities. A context that was safe, social, learning-based and family-centred, activated program mechanisms amongst children and youth with disabilities to elicit perceived outcomes across all levels of the ICF. Whilst optimising participation in physical activity is a primary outcome of the LEM, the refined program theory demonstrated that outcomes of interest to children and parents extended further. Outcomes from this study may be of particular value for policy makers, researchers and practitioners, for further testing and utilisation of this theory in interventions and services aiming to enable participation in physical activity for children and youth with disabilities.

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5.7 References


Chapter Six

Facilitating participation in physical activity for children and youth with disabilities: A Theory of Parent Learning and Empowerment

This manuscript was submitted for publication in the *Scandinavian Journal of Occupational Therapy*, in November 2016, and is currently under review:


The PhD candidate, Claire E Willis, accounted for 80% of the intellectual property associated with the final manuscript (the primary individual involved in the study design, data collection, data analysis, data interpretation, and manuscript preparation and revision). Collectively, the remaining authors contributed 20%. The formatting and references of this chapter follow the guidelines for submission to the *Scandinavian Journal of Occupational Therapy.*
FOREWORD

In understanding program mechanisms from the perspectives and behaviours of those receiving the intervention, Chapter Five focussed on the outcomes of the child. In order to understand this from a truly family-centred perspective, Chapter Six aimed to describe the experience of parents participating in the LEM intervention. The chapter explores in detail the parent-described process of evolving as facilitators to their child’s participation in physical activity. The results are presented as a theoretical model, to demonstrate to knowledge users how parents can be encouraged to adopt facilitative roles, and how this promotes the continuation of physical activity practices following interventions.

Note: This chapter comprises data that was collected from the same parent sample in Chapter Five. Specifically, data from interviews were collected concurrently; part one of the interview guide encompassed questions and prompts relating to the experience of the child (Chapter Five), and part two was focussed on the experience of parents (this chapter). Importantly, all data contributing to results is independent across both chapters. While the sample and data collection were interrelated, the findings are stand-alone. This is the final paper in the series arising from the evaluation of the LEM intervention.
6.1 ABSTRACT

Aim: This study aimed to explore how an intervention supports parents of children and youth with disabilities to become facilitators of physical activity participation.

Methods: A grounded theory approach was used. Participant recruitment occurred through purposive and theoretical sampling of parents participating in the Local Environment Model intervention at Beitostolen Healthsports Centre in Norway. Sources of data were derived from the triangulation of semi-structured interviews and participant observation. Data analysis was an iterative approach of constant comparison, where data collection, memo writing, open, axial and selective coding analysis, were undertaken simultaneously. Findings were consolidated into a model describing the central phenomenon and its relationship to other categories.

Results: Forty four parents (26 mothers and 18 fathers) of 31 children with a range of disabilities (mean age 12y 6m (SD 2y 2m); 18 males) participated in the study. Thematic concepts uncovered in this study constructed a theory describing the social process of parent learning and empowerment, comprising three primary components; (i) active ingredients of the LEM intervention that enable learning and empowerment to transpire, (ii) parent learning and empowerment, and (iii) related outcomes.

Conclusion: A family-centred approach encompassing family-to-family support enhances physical activity participation outcomes for children and youth with disabilities.
6.2 INTRODUCTION

Participation in physical activity is necessary for the optimal physical, emotional, and psychosocial development of all children and youth. The experience of participation is influenced by child and family interests and priorities, and optimised by experiences that foster a child’s engagement, connections with others, learning and skill development, and enjoyment [1]. Yet for children and youth with disabilities, it has been reported that 76% to 99% of their waking hours is spent in sedentary activity [2], and participation in physical activity is significantly less than their typically developing peers [3, 4]. Alarmingly, the prevalence of obesity in children with disabilities has been documented to be up to six times higher than typically developing children [5]. An urgent call for action has recommended that research focus on developing physical activity promotion strategies across the lifespan, and build an evidence base supporting the development of effective interventions [6, 7]. Of particular importance is the development of approaches that enable the translation of practices acquired from interventions into sustained participation and lifelong habits [6].

The International Classification of Functioning, Disability and Health-Child and Youth version (ICF-CY) is frequently used to conceptualise the barriers and facilitators of participation in physical activity for children and youth with disabilities [8]. Systematic reviews document that factors across all levels of the ICF-CY influence physical activity for children with intellectual and physical disabilities [9, 10]. The actions, behaviours and concerns of parents have specifically been identified as both barriers to and facilitators of physical activity [9, 10]. While more barriers to participation are evident, there are a number of identified supports that enhance a child’s physical activity participation, including; the presence of parental support and motivation, participating in physical activity as a family, parents creating opportunities for their children to be active, and parental perseverance and assertiveness in advocating for a child’s participation in physical activity [9, 10]. As parents make up the immediate environment of a child and play the most influential role in their development and wellbeing [11], interventions attempting to optimise physical activity participation may be required to be family-centred.

Family-centred theory underpins many models of paediatric service delivery, recognising and acknowledging the needs of all family members and not just those of the child with a disability [12, 13, 14]. Key principles of family-centred services are that families are central to the child’s life and are the primary source of support, approaches are competency enhancing and strength-focused, and there is facilitation of family-to family support and networking [14, 15]. Despite the wide acceptance of the importance of family-centred approaches to health and functional outcomes of children with
disabilities [13], few studies have examined the effectiveness of interventions founded on this theory to improve physical activity outcomes in children and youth [16, 17]. In typically developing children, most evidence of effective physical activity interventions comes from those targeted at families [18]. While the development of facilitative parents has been proposed as a strategy that may improve participation outcomes for children with disabilities [19, 20], our knowledge of how we can enable parents to embody facilitative roles is lacking.

Understanding how an intervention triggers change is an essential component of the evaluation process [21]. The identification of active ingredients and understanding how they exert their effect is required for the design of more effective interventions, and to enable their application across settings [22]. Beitostolen Healthsports Centre (BHC) is a rehabilitation centre in Norway, seeking to enable lifelong activity and participation in local environments for people with disabilities. The paediatric program (the Local Environment Model, LEM) is a goal-directed, family centred intervention that enables children and youth with disabilities to participate in physical activities in their local communities [17]. The family-centred context of the LEM attempts to ensure that knowledge, skills and experiences of children and caregivers acquired during a stay at BHC are translated into family lifestyles and local settings following the intervention. This is driven by a derivative of situated learning theory known as ‘Communities of Practice’ [23]. Parents of children with disabilities from the same municipality are actively engaged in the preparation, intervention and follow-up stages of service delivery, connecting through mutual engagement, a joint enterprise and a shared repertoire [23]. Given the multiple components of this intervention, the original question of this study was broad and unassuming [24], asking ‘how do parents experience the LEM’? As the research progressed, and parents described a process of evolving as facilitators, the research question gradually became more focussed [24]. Subsequently, this study aimed to explore how the LEM encourages parents to become facilitators of a child’s participation in physical activity.

6.3 METHODS

6.3.1 DESIGN

A grounded theory approach was used for this study. Grounded theory has a realist orientation and is intended to produce knowledge of processes [24, 25]. The full version of grounded theory [25] was utilised in this study, and sources of data were derived from ethnographic data collection methods, including semi-structured interviews and participant observations. Grounded theory and ethnography are highly compatible, in that ethnographic studies can provide a thick description of data that is
required for grounded theory analysis [26, 27]. Through application of these methods, we generated a theory to describe the process that enabled parents to adopt roles as facilitators of their child’s participation in physical activity.

Ethics approval for this study was obtained from the Princess Margaret Hospital Human Research Ethics Committee (2013099), The University of Western Australia (RA/4/1/6556), and the Norwegian Regional Committee for Medical and Health Research Ethics, section South-East C (2014/1342-1).

6.3.2 PARTICIPANTS

Purposive and theoretical sampling was used to select participants for this study. In phase one of data collection, participants were selected to participate if they were (i) the accompanying guardian and (ii) the primary caregiver of a child participating in the LEM intervention at BHC (children participating in the LEM are 6-17 years of age and typically have a range of disabilities). Primary caregivers who met the inclusion criteria were first informed about the study by the Director of Paediatric Teams, and received an information sheet that had been translated into Norwegian. In phase two of data collection, participants were theoretically sampled to refine emerging categories relating to how participation in physical activity was, or would be, maintained following the intervention. Theoretical sampling ceased upon reaching theoretical saturation, when no new properties of the categories were identified [28].

6.3.3 DESCRIPTION OF INTERVENTION

The LEM is an intervention developed by BHC that focuses on enabling participation in physical activity for children and youth with disabilities. One month prior to the program, representatives from BHC travel to the community of the group of families coming to stay, to prepare and engage local communities in the service delivery cycle. The intervention is delivered at BHC, where groups of 8-10 children and their parents stay for 19 days. The intervention is based on the child’s goals, but also designed to introduce children and their families to novel physical activities and participation experiences. The children’s stay is intensive; activities are scheduled for 2-5hrs a day, six days a week.

At BHC, parents participate in the ‘Parental Guidance Program’, to learn how to facilitate their child’s participation in their home and community. Additionally, a short training course (optional) is
provided to service providers involved with the child in their local communities to encourage
environmental adaptation and collaborations between service providers from the same municipality.

Three months after families return to their local communities, the same field team travels back to the
community for a follow up meeting with children, their parents, service providers, and the region’s
representative from the Norwegian Federation of Sport. This meeting is used to map each child’s
progress towards achievement of their follow up plan, discuss any barriers families may be
experiencing, which will continue to be followed up by local communities. The second objective of
this meeting is to begin the plan for the child’s second stay at BHC that occurs approximately 1.5
years after the first, in the opposite season. The intervention timeline can be seen in Figure 6.1.

![Figure 6.1 Timeline of the Local Environment Model (LEM) intervention.]

BHC, Beitostolen Healthsports Centre; LPSP, local paediatric service provider

6.3.4 DATA COLLECTION

The first author (CW) spent a total of 15 weeks at BHC undertaking data collection. This occurred
over two separate time periods (summer/autumn and winter/spring). As well as accounting for
intervention-specific seasonal differences, this also enabled the researcher to return to the field to
validate the theory that emerged from the initial stages of data analysis [24]. The first author lived at
BHC during this time, and participated in the daily intervention and leisure practices of parents and
children staying at the Centre. Proficiency in the Norwegian language aided in the cultural immersion
of the researcher. Data collection involved the triangulation of semi-structured interviews and
participant observation, employed over two time points (Figure 6.2).
6.3.4.1 INTERVIEWS AND FOCUS GROUPS

Interview guides were developed in collaboration with a consumer-driven steering group, including parents of children with disabilities. The interview guide was piloted with a manager at BHC to obtain feedback of utility prior to use in data collection. The interview guide covered broad topics relating to the experience of the parents in the program, and was revised when new topics were raised during the interviews. Topics discussed during the interviews with parents at BHC are outlined in Table 6.1.

<table>
<thead>
<tr>
<th>Guiding topic</th>
<th>Key prompts</th>
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<tbody>
<tr>
<td>Experiences of participation generally</td>
<td>Reasons for applying for a stay at BHC</td>
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<tr>
<td></td>
<td>Expectations of the program</td>
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<tr>
<td>Experience in the program at BHC</td>
<td>Description of experience</td>
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<td></td>
<td>Influence of service-related factors</td>
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<td></td>
<td>Influence of the human and physical environment</td>
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<td></td>
<td>Managing other commitments</td>
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<tr>
<td></td>
<td>Recommendations for change</td>
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<tr>
<td>Experience in local communities</td>
<td>Barriers and facilitators (experienced, or perceived)</td>
</tr>
<tr>
<td></td>
<td>Role of parent/BHC/LEM group</td>
</tr>
<tr>
<td></td>
<td>Role of local paediatric service providers</td>
</tr>
<tr>
<td></td>
<td>Outcomes from previous stay (if applicable)</td>
</tr>
<tr>
<td>Outcomes of the stay</td>
<td>For parent/family</td>
</tr>
</tbody>
</table>

The first author, a female PhD candidate proficient at qualitative data collection, undertook all interviews. The interviewer (CW) had no relationship to participants prior to their involvement in the LEM. Semi-structured interviews explored the parents’ experience in the LEM, and as it emerged, their role in their child’s participation in physical activity. Semi-structured interviews were conducted with parents at a mutually convenient time in a private meeting room at BHC. Norwegians have a
very high proficiency in English [29], thus participants were offered the choice to conduct interviews in Norwegian or English. The majority of parents elected to undertake interviews in English. Three parents chose to conduct the interview in Norwegian. As Norwegian is not the primary language of the first author, a translator (MM) was present in these interviews to ensure accurate interpretations.

The first author transcribed each interview from the recordings verbatim. Norwegian interviews were transcribed in Norwegian and translated to English by the first author. Whilst researchers who also act as translators are rare, this method enhances the validity of interpretations as it allows close attention to cross cultural meanings and interpretations [30]. English translations were then back-translated by the translator that was present in the interviews (MM). Approximately half of the interview participants had the opportunity to review their transcribed interview, and made no changes.

6.3.4.2 Participant observation

During phases 2 and 3, overt observational methods were used to describe and link emerging categories proposed in the interviews to actual parent behaviours during the intervention [31]. Observations of parents in this study occurred in a range of settings; (i), in the local communities of families participating in a stay at the centre, during the pre- and post-intervention meetings; and (ii), at BHC, during the intake and evaluation interviews, during structured intervention activities, and periods of informal interactions and communications. Conversational interviews with parents also occurred spontaneously in these settings. Observations of parents at BHC occurred during the hours of their typical day, 8am-8pm.

Detailed field notes were documented following each observation period, containing descriptions of events, conversations and reflections. Alongside this, memo writing throughout the process of data collection maintained a record of preliminary thoughts in relation to observation and interviews, and provided reflections on the adequacy of the research question [32]. Daily contact with participants meant it was possible to check and confirm the meanings of participant behaviours, and adjust or add to the categories and their properties explored in the memos accordingly [32]. Memos were both original and integrative (of earlier memos or ideas), and used both words and diagrams that documented the emerging theory [32].

6.3.5 Data Analysis

6.3.5.1 Interviews
Data analysis was an iterative approach of constant comparison, where data collection, coding and analysis were undertaken simultaneously [26]. NVivo (QSR International Pty. Ltd., 2015) software assisted with handling interview data and field notes. Discussions were transcribed verbatim and constantly compared with field notes and memos. Transcripts, field notes and memos were read multiple times, with this inductive approach allowing meanings to emerge from the data [31]. Initial coding of the interview data was conducted via a grounded theory approach in exploration of emerging categories and their properties [26, 28]. Data were coded using an open coding model, with attention to constant comparison between participants [24, 26]. Analysis of deviant or negative cases enabled the revision, broadening and confirmation of the patterns emerging from data analysis [33]. During open coding, data were triangulated with observation data to identify additional subcategories and agreement amongst source material [24]. Axial coding was used to group ideas based on the constituent clusters addressed by participants, with constant comparison of categories and relationships with ongoing additions of ethnographic evidence [24]. Selective coding allowed the detailed development of categories, around the core categories and central phenomenon of the study [24]. The emerging theory guided additional data collection (e.g. new interview topics such as the role of multiple stays) to support further development of the theory and to reveal discrepancies that needed clarification. As grounded theory suggests, the core category and it’s unification with other categories directly informed the creation of the model presented in the results section (Figure 6.3) [32]. One author coded all interviews first and a second author reviewed and checked the coding.

6.3.5.2 Participant observation

Descriptive and coding analysis of observation data recorded in the form of field notes occurred away from the clinical field, but onsite at BHC. This involved elaborating upon, completing and refining descriptions of fieldwork experiences, reflecting upon the emotional responses of parents, and examining patterns in behaviour. Observation data was coded in the same manner as the interview transcripts.

6.3.5.3 Memos

Throughout the process of data collection and analysis, the first author kept a written record of theory development. This included the exploration of categories, tracing their emergent relationships with other categories, and keeping a record of the progressive integration of higher- and lower-level
categories [32]. The memos captured the first authors’ progressive synthesis of the data as analysis occurred concurrently with data collection [32].

6.3.6 TRUSTWORTHINESS

A number of procedures were employed to ensure the trustworthiness of these methods. Prolonged engagement, persistent observation and the triangulation of data sources strengthened the credibility of interpretations [34]. Purposive and theoretical sampling enhanced the transferability of the data. Dependability was enhanced by the researcher documenting reflections in memos and demonstrating an audit trail of the research methods [35]. Additionally, emerging and final results were presented to the steering group in Australia as a method of confirmability [35].

6.4 RESULTS

6.4.1 PARTICIPANTS

Forty four parents of 31 children participated in the study. All caregivers that were approached were parents, and all agreed to participate. Of the 44 participants, 13 were parent dyads. A total of sixteen mothers and two fathers participated in semi-structured interviews. Of these, 5 were single parents, and 7 of the parents had another caregiver (partner, grandparent, or carer) stay at BHC for one week or more. Family demographics and characteristics of children (n=31) are detailed in Table 6.2.
Table 6.2 Participant demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Category</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent relationship to child</td>
<td>Mother</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>18</td>
</tr>
<tr>
<td>Residential setting of family</td>
<td>Population 500,000-1,000,000</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Population 250,000-499,999</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Population 50,000-249,999</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Population &lt;50,000</td>
<td>8</td>
</tr>
<tr>
<td>Characteristics of children</td>
<td>Age, y:m (SD)</td>
<td>12:6 (2:2)</td>
</tr>
<tr>
<td></td>
<td>Age range, y</td>
<td>6-17</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Child's primary health condition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cerebral Palsy</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>GMFCS I/II/III/IV/V</td>
<td>5/4/1/1/1/1</td>
</tr>
<tr>
<td></td>
<td>Acquired brain injury</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Intellectual disability*</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Number of stays at BHC (n)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n=1st</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>n&gt;1</td>
<td>11</td>
</tr>
</tbody>
</table>

GMFCS, Gross Motor Function Classification System; SD, standard deviation; BHC, Beitostølen Healthsports Centre. *including Downs Syndrome, Fragile-X syndrome, and craniosynostosis.

6.4.2 THE THEORY OF PARENT LEARNING AND EMPOWERMENT

The thematic concepts uncovered in this study constructed a theory describing the social process of learning and empowerment of the parents participating in the LEM. The theory encompasses three primary components; (i) active ingredients of the LEM intervention that enable learning and empowerment to transpire, (ii) learning and empowerment, which refers to the social process through which parents gained knowledge, understanding and control over their role as facilitators to their child’s participation in physical activity and (iii) outcomes of the process, including how the practices acquired from the intervention continued as a part of family lifestyles in local communities, and the relationship to parent satisfaction with service delivery. The theory of parent learning and empowerment is described in detail below and illustrated in Figure 6.3.

6.4.2.1 ACTIVE INGREDIENTS

Six active ingredients were described by parents that enabled them to learn and be empowered as facilitators of their child’s participation in physical activity. These included; a balance of parent
involvement in the intervention, a continuum of support, groups from the same geographical region, participation as a focus and a priority, exposure to opportunities and possibilities, and activity and participation throughout life. Active ingredients, operational definitions and sample quotes are described in detail in Table 6.3. Quotes referencing children are accompanied by the child’s age (y), and whether they have a physical disability (PD) or intellectual disability (ID).
### Table 6.3 Active ingredients identified by parents that enabled learning and empowerment

<table>
<thead>
<tr>
<th>Active ingredient</th>
<th>Operational definition and outcome</th>
<th>Sample quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Parent involvement in the intervention: a balance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents are involved in some parts of the structured physical activity program:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Parent involvement in the activity program:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Enabled learning and recognition that they would be able to facilitate participation in the child’s participating in the same activity in their home and community</td>
<td>&quot;I feel that it is so important for [child, 17y, ID] that we are with her to see this, so we can continue when we go home&quot;</td>
<td></td>
</tr>
<tr>
<td>o Allowed parents to witness capabilities of their child, an important process for alleviating concerns and fears associated with safety, skills of professionals and the ability of the child to manage the activity</td>
<td>&quot;But mostly, it has helped me become less protective of my son. Now I can see he can do things on his own. So a part of this has been me letting go, after seeing he can do things on his own&quot;</td>
<td></td>
</tr>
<tr>
<td>• Components of the intervention whereby parents were not involved allowed parents to understand:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Children can often be more motivated by staff members, students, and peers to try an activity or achieve a goal</td>
<td>&quot;We as parents can only come so far, but the staff here, they can get them much further&quot;</td>
<td></td>
</tr>
<tr>
<td>o It is was important for children to have opportunities to do things without their parents present</td>
<td>&quot;I think when they get older, sometimes it’s nice to be able to do things without their parents”</td>
<td></td>
</tr>
<tr>
<td>o Time without children allowed time for their own respite, self-reflection and social activities</td>
<td>&quot;Parents have to be on their own sometimes. We need breaks and some space”</td>
<td></td>
</tr>
<tr>
<td><strong>2. Continuum of support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents receive support pre-, during and post-intervention from a service, systems and policy level:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Support pre-intervention:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Provided an opportunity for parents to raise their concerns and uncertainties, and receive answers to questions.

- Support during the intervention:
  - Resulted in minimal difficulties in taking time away from their workplace to participate in the stay at BHC. Due to government policies, there is no financial contribution required from families, and parents continue to receive their wage from their employer during the intervention. Families of all socioeconomic positions can access the service.
  - A model of service that was accommodating to the individual needs and preferences of each child and family elicited a high level of satisfaction from parents.
  - Provided parents with knowledge of services in their own communities and encouraged parents to create ongoing opportunities for their child to be active.

- Support post intervention:
  - Encouraged parents to implement practices acquired at BHC into their lifestyles, knowing the support from BHC was ongoing.
  - Fostered the transition of the role of support to be adopted by local communities (e.g. NSF regional representative, local rehabilitation centres).

“We met as a group much before. But I was sceptical to come you know. But I thought, let’s just give it a try. And after that meeting, I was a little bit like ‘why didn’t we come [to BHC] before?’

“We have good arrangements for this…it’s our rights”

“I think it’s great because you have this conversation with the whole team when you get here, and you have this conversation when you are halfway to see if the goals are still right and if there is anything you want to change, and then you have a conversation before you go home”

“We are getting help [at BHC]. They know the places in our community that are doing those activities, so they can lead us in the right direction or link us to the right group”

 “[The follow up] makes you feel like you are being taken seriously, and that [BHC] really want to do this the right way. You don’t just come and then you go home and then everyone forgets you”

3. Groups from the same geographical region

Groups are assembled from the same regional area to unite families and community members who have similar experiences, without the benefit of a shared practice:
• The development of an ongoing support network for parents:
  o Enabled the exchange of experiences between parents of children of a variety of ages and abilities and encouraged parents to learn from each other
  o Facilitated the development of a social group and enjoyment in physical activity

• Parents adopt a role of knowledge broker:
  o Parents become confident in their ability to impart their knowledge to other community members, for the benefit of the community
  o Developed an attitude of ‘strength in numbers’: parents were no longer alone in their quest to advocate for opportunities for their child
  o Awareness of the role of communities
  o Enabled parents to recognise that without the support from health professionals, services and systems in their home communities, barriers surrounding accessibility and accommodation may still be present.

“*We are able to talk to other people who have the same problems. We are all in different stages I think. And we learn from each other when we talk*”

“*From being a group [at BHC], we know each other very well and we go on many trips together at home. We know each other’s kids very well and we cooperate together. We are a very good team*”

“I think this is a good idea for us to come here as a local community. Because it means we have more people that come here and learn about more activities and how we can do them, and then we can teach others in our community”

“It’s just as important that the local service providers, and the team around the child at home, come to a place like this and learn”

4. Participation is a focus and a priority

Participation is the focus of the intervention. This encouraged parents to:

• Reflect on the importance of participation amongst other priorities
  “To get in the bubble, to focus on physical activities and participation…I think that’s important in life. And we forget about that sometimes in the routines at home. So it’s good to come in a new bubble that helps you focus on that”

• Accept that changes in participation outcomes requires time
  “That is what is so fine with place - you make many small steps, and while you are here they build up to a really big one”
Understand that creating opportunities for a child to participate in physical activity impacts other aspects of their lives in a positive way.

Participation in physical activity is (or becomes) a priority for parents:

- Parents become aware of the benefits of physical activity
  
  “I just wish we had known about this place a long time ago, when [child, 16, ID] was a little girl. So we could have got the benefits earlier”

- Parents are motivated and inspired to continue participating in physical activity
  
  “We will start on Monday. And I’ll buy ten personal training sessions. They are expensive but it will be worth it”

- Parents are determined to explore and access opportunities in their community to transfer their acquired knowledge and experiences into lifestyle changes.

“I just wish we had known about this place a long time ago, when [child, 16, ID] was a little girl. So we could have got the benefits earlier”

As children increased in age, and/or parents had stayed at BHC multiple times, parents applied their knowledge to provide solutions that address service and time related barriers they experience on their return to their local communities.

“What also would be great, would be if we had something like this near to us, and you just came for the day”

5. Exposure to opportunities and possibilities

Exposure to, and the opportunity to participate in, a range of physical activities with the appropriate supports (specialised staff, adaptive equipment and personalised instruction), enabled families to:

- Learn how to facilitate participation in a variety of activities for their child
  
  “My children have a big platform of activities they can try here, with a lot of good equipment and assistants who make sure we learnt how to do the activities correctly. So then we have a lot of different activities to continue with at home”

- Find enjoyment in physical activity, and find activities that the family can do together
  
  “We wouldn’t be quite as motivated for skiing if we hadn’t been here”

- Experience an ‘out of the ordinary’ feeling of inclusion
  
  “At home, we don’t often get invited to things with other children, but here, we are included in everything”

- Gain new understandings of possibilities that were not previously considered or believed to be achievable
  
  “[BHC] is all of the possibilities you can think of”
Opportunities for informal and unstructured activity time within the intervention allowed parents to:

- ‘practice’ facilitation of physical activity pursuits with the supports (parent group) of the intervention environment

  “And yesterday after the [formal program], me and another mother taught him [child, 14, PD] to ride a bike with only two wheels!”

6. Activity and participation throughout life

The LEM intervention entails children and families returning to BHC to participate in activities available only in the opposite season (e.g. winter for skiing). Additionally, parents and children can return to BHC through other programs. This enables parents to understand and recognise:

- The importance of physical activity participation throughout the lifespan

  “I think it’s important that these opportunities exist throughout life for people to be active”

- The value of what the intervention provides to a child and their family

  “There will always be steps made with each stay. Not only that [children] try different things because of the seasons, but because they build on the stones from what they have already learnt”

- That a child’s activity and participation preferences will change throughout the course of their life

  “So right now we feel like we are on track to start the swimming group and we feel like after being here, we can do that. But later the kids might want to do new activities, and we might need some guidance in how to do that”

- That further support and guidance may be required to facilitate this

BHC, Beitostolen Healthsports Centre; NSF, National Sports Federation; PD, physical disability; ID, intellectual disability.
6.4.2.2 LEARNING AND EMPOWERMENT

Learning and empowerment was the process by which parents obtained access to knowledge, skills, and resources that enabled them to gain positive control over their roles as facilitators of their child’s physical activity participation. From the active ingredients of the LEM, it was clear that parent learning and empowerment was a social process. Learning evolved from social engagement, where parents could ‘discuss differences and similarities and what we can do better, and how we can cooperate with each other to make it better’. Similarly, exposure to a variety of opportunities enabled parents to master new understandings about the possibilities for physical activity for the whole family. Participation in physical activity, the focus of the intervention, facilitated the growth of new knowledge for parents, and this typically stimulated the prioritisation of physical activity for families. Empowerment was initiated alongside other parents through whom support, mutual encouragement and confirmation of perceptions and experiences were received. Empowerment was a result of not only a parents needs being met (i.e. being provided with skills and knowledge about how to facilitate physical activity participation, support pre- and post-intervention), but also from highlighting the existing abilities of themselves and their child, and the resources already available in a families local environment (support and relationships, services). Following the intervention, ongoing participation was anticipated to continue as a shared enterprise of the parent group (‘now I know we can do it’), particularly in their desire to ‘show the local communities how to see our kids better’. Ultimately, the process of learning and empowerment increased parents’ belief in their ability to enable their child’s participation in physical activity in their local environment:

“So now, I think [to myself] ‘it is possible’... it helps me to understand, [child] can do it, of course she can. And when some other parent at home says to me my child cannot climb – of course she can climb. Maybe only 50cm but she can do it if she wants to. Everybody can do a little bit. And I think that it’s important that we parents learn too. We see that it is possible. Just go for it. And if the results, if they are small, it’s not so small for that person. And over time, you learn, and you can do more. You build” – parent

6.4.2.3 OUTCOMES

PARTICIPATION IN PHYSICAL ACTIVITY IN LOCAL ENVIRONMENTS

Feeling confident and equipped with the skills, knowledge and support to enable their child to participate in physical activities at home and in the community was a primary outcome for parents.
Parents for whom it was their first time participating in a stay at BHC described strategies and plans in relation to what would happen when they returned home in an assured manner. When conveying this, parents were exhilarated, uplifted and excited about the possibilities this would now create for their child and their family:

“[Child, 14y, ID] likes to kayak. So we are going to get a kayak. We have talked before about buying a canoe. But [at BHC], trying them both, we have learnt that a kayak is better for him. So we are going to get a kayak!”

Parents whom had visited BHC a number of times typically described positive physical activity experiences in their home communities. Many described that coming to BHC helped them to realise that ‘most of the activities we learn here are things we can do at home’. Parents felt participating in physical activity in their local communities as a family was a more manageable process:

“It’s amazing. Since BHC we have been able to do lots of cross country skiing, and bicycling and swimming and other activities like that”

A number of environmental barriers existed in local community settings. Parents explained that often, ‘the biggest problem is distance’, particularly for seasonal activities where ‘we have to travel a long way to get to the ski slopes’. For goals relating to structured physical activity programs, negative attitudes and access to specialised staff were reported to be an ongoing barrier. However, parents described BHC as ‘an engine that gives us new spirit to go on’, and that the LEM enabled them to continue to persevere in the facilitation of their child’s participation in their local communities.

**ACTIVE ENGAGEMENT AND DISPERSION OF THE LEM GROUP**

The life cycle of each LEM group was determined by the value it provided to parents and children. Parents who had previously been to BHC as a part of the LEM described the ongoing engagement of the group for the children as vital, because ‘being able to maintain these connections is so important for [child], and his motivation and participation when he goes home’. Support and relationships within the group commonly facilitated ongoing participation:

“We went skiing, walking in the forest, we were sleeping overnight outdoors without a tent in the summer time...we have done a lot of things together with all of the kids”

One group described that the initial coalescing of the group when its members were young children had been highly influential for their futures as adolescents and young adults:
“So there are five kids, and we are looking to build a house together, with six apartments. Five for the children together, and one for a person who is working in the house [as a carer]. It has taken a lot of time but things are happening now. And that’s really comforting to think of, because the kids know each other so well, and the parents as well, and it’s so safe to think we have a future together”

Some explained the gradual dispersion of the group over time, from regularly engaging in joint activities and being ‘a very tight group’, to no longer engaging as intensely. Parents did not describe this in a negative manner, explaining that the group was still alive as a centre of knowledge, and continued to communicate with members as the ‘exchange of experiences is useful’.

Of the parents for whom this was their first time participating in the LEM intervention, a number of strategies, including electing one parent to be the group coordinator and ‘a Facebook group, where we can share our photos but also stay in touch’ were enthusiastically implemented at BHC in the hope to keep the group active and connected after the intervention.

SATISFACTION WITH SERVICE DELIVERY

Parents expressed an extremely high level of satisfaction regarding all aspects of the LEM throughout their time in the intervention. The most common word to describe the experience at BHC was ‘perfect’. The operationalisation of the active ingredients contributed to the positive experiences:

“I think the whole package is important and it works”

Parents attending their first stay were often unsure and hesitant coming into the program. Upon leaving, all parents (regardless of how many times they had visited BHC), felt equipped, self-assured and satisfied with the outcomes of the intervention:

“I can’t think of anything more I would want to get out of this whole experience”

Parents were often very emotional when describing what the whole experience meant to them, their child and their family. It was extremely important to parents that other parents of children with disabilities were informed about the Centre, and were made aware of its impact:

“We didn’t know about Beitostolen Healthsports Centre. But now we do. And now we shall recommend it to all of the other parents who have children who have special needs”
Participation is a focus and priority.

A balance of parent involvement.

Groups from the same geographical region.

Continuum of support.

Exposure to opportunities and possibilities.

Activity and participation throughout life.

Parent learning and empowerment.

Participation in physical activity in local environments.

Active engagement and dispersion of the LEM group.

Satisfaction with service delivery.

Figure 6.3 Theory of Parent Learning and Empowerment
6.5 DISCUSSION

The Theory of Parent Learning and Empowerment was constructed from this study. The theory encompasses three primary components; (i) active ingredients of the intervention that enable learning and empowerment to transpire, (ii) the social process of learning and empowerment, and (iii) process outcomes. This study demonstrated that learning and empowerment of parents in the LEM intervention evolved from six ingredients; parent involvement in the intervention (a balance), a continuum of support, intervention groups from the same geographical region, participation as a focus and a priority, exposure to opportunities and possibilities, and activity and participation throughout life. Ultimately, outcomes of the process of learning and empowerment, including parent satisfaction with service delivery, enabled parents to facilitate (or believe in their ability to facilitate) their child’s ongoing participation in physical activity.

This study describes novel findings as to how parents can be empowered to embody facilitative roles to enable their child’s participation. The family-centred nature of the intervention was pivotal to this process, adding empirical support to previous research that emphasises the need to consider the whole family if we are to improve the participation outcomes of children with disabilities [1, 36, 37]. Active engagement in parts of the intervention enabled parents to learn and practice facilitation in situ, which simultaneously alleviated parents’ concerns and fears associated with their child, the activity, and the environment. This is a unique approach for participation interventions, which typically focus solely on the child during the intervention component [38, 39]. The involvement of parents in the participation-focused intervention supported the development of awareness of the benefits of physical activity, prompting reflections on the importance of participation, amongst other priorities. This is an important finding, as if families do not inherently value physical activity, they are unlikely to engage in, or sustain, physical activity behaviours [40]. Engaging parents in interventions to optimise physical activity participation may not only empower them to adopt facilitative roles, but also address many family-related barriers that previously hindered this.

Findings from this study demonstrate that learning and empowerment evolved from social engagement. Parents were exposed to, and had the opportunity to participate in, a range of physical activities with their children, other families, and with and without the presence of program staff. The group-based design not only created a social and support network for parents, but enabled them to learn from and empower each other. This aligns with the work of Parsons et al. (1991), who described that empowerment is initiated with others through whom support, mutual assistance, and confirmation of perceptions and experiences are received [41]. Interestingly, models that describe parent
empowerment as a primary goal alongside child participation outcomes do not include elements describing the support parents and families may require from other families in order to achieve this outcome [1, 37]. In this study, it was the support from others in similar situations that empowered parents to advocate for the full inclusion of their child in their community. For parents, empowerment may not only be a matter of their needs being met [42]; the accessibility to social support may act as a key determinant to this process and its outcomes.

A child (and family’s) ongoing participation in physical activity in local environments was a central outcome of the learning and empowerment process. While rehabilitation therapists are documented to be primary facilitators of change [1], this research proposes a model whereby collaboration encourages parents to take on this role. For this to occur, our findings emphasise the significance of the ‘community of practice’ (CoP) of which the intervention was entrenched in [23]. Prior to a stay at BHC, families faced similar situations without the benefits of shared practice. The LEM brought families together, enabling them to explore their connectedness, negotiate their ‘community’ and develop a ‘practice’. Following the stay at the centre, not all families engaged as intensely, yet each group continued to stay connected, producing a resource for knowledge and encouragement for ongoing participation in physical activity upon their return home. While it is widely acknowledged that children and youth will experience health and psychosocial benefits from participating in physical activity, interventions alone are not enough to sustain these benefits [43]. The application of CoP to foster participation in physical activity is unexplored across typically developing and disability literature, but may represent an effective approach for sustaining participation in physical activity for children with disabilities and their families.

Parents in this study reported a high level of satisfaction regarding the process and structure of service delivery at BHC. These results are consistent with other family-centred and service evaluation literature, describing positive and directional relationships between empowerment, service delivery satisfaction, and parent and child outcomes [44, 45]. As satisfaction is an outcome that can be measured easily across settings [46], this could also be considered as an indicator of effectiveness for future interventions. Further, while the process of empowerment is most often studied using qualitative methods [47], there are a tools that can quantify the outcome of parent empowerment [48]. The Family Empowerment Scale can provide information relating to the changing status of empowerment of family members caring for children with disabilities [48]. Future research in family-centred participation interventions should attempt to measure the relationship and impact of parent empowerment to child, parent and service-related outcomes of interest.
It is important to note that the continuum of support that families received in this intervention was largely due to standards in place at a policy level. Reducing social inequalities in health and access to care and services is a central theme of health policy in Norway, and reflected in the active ingredients identified in this study. The Individual Care Plan was introduced in Norway in 2001, giving children and families the right to be involved in the process of shaping their own services [49, 50]. As parents recognised in this study, a child’s participation preferences and needs change over time, and access to support across the lifespan is required. As a result of the services, systems and policies in place surrounding rehabilitation in Norway, this may be more likely to occur. Encouragingly, these policies are not exclusive to this country; current trials of the National Disability Insurance Scheme represent a ground-breaking reform of disability support services in Australia [51]. This was initiated by from campaigns from advocates, whereby evidence relating the lived experience of disability, including identification of strategies to support participation, contributed to momentous and pervasive policy change [51]. Support at a service, systems and policy level may be essential for parents to continue to receive the support they require to facilitate their child’s physical activity participation, and for children to do this independently in the future.

6.5.1 LIMITATIONS

The findings from the current study should be interpreted within the parameters of a number of considerations. This research was conducted in one rehabilitation centre in Norway, which may limit our interpretation of parents’ collective perspective and resulting experiences. Secondly, we were not able to perform a complete member checking process of interview participants. However, the triangulation of data sources and the prolonged engagement at the site (inclusive of persistent observation) enhances the credibility of the data and subsequent results. Finally, there were a greater number of female caregivers involved in the study, which may have impacted our understanding of the program with limited perspectives from male caregivers. Of note, this sample was reflective of the demographics of caregivers staying at BHC.

6.6 CONCLUSION

This study describes the Theory of Parent Learning and Empowerment, a social process that encouraged parents to adopt facilitative roles to enable their child’s participation in physical activity. A family-centred approach, including developing family-to family support and networking, may be required to optimise physical activity participation outcomes for children and youth with disabilities.
Outcomes from this study may be of particular value for policy makers, researchers and practitioners, for further testing and utilisation of this theoretical framework.

ACKNOWLEDGEMENTS

The authors wish to thank all of the participants who took part in this study. Thank you to the paediatric teams at BHC that accommodated the first author during the periods of data collection, to Team Leader Tor Erik Nyquist (MSc) for his support and assistance in the organisation of data collection, and to APA specialist Mette Miklos (MSc) for her role in language translation. In addition, we wish to acknowledge The Participate Project Steering Group for their valuable input, direction and discussion.

DECLARATIONS

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6.7 References


Chapter Seven

Involving consumers and the community in childhood disability research: Impacts, outcomes, processes, and context.

This manuscript was submitted for publication in Disability and Rehabilitation, in November 2016, and is currently under review:


The PhD candidate, Claire E Willis, accounted for 85% of the intellectual property associated with the final manuscript (the primary individual involved in the study design, data collection, data analysis, data interpretation, and manuscript preparation and revision). Collectively, the remaining authors contributed 15%. The formatting and references of this chapter follow the guidelines for submission to Disability and Rehabilitation.
FOREWORD

As described across all chapters, consumers and the community were involved at all stages of the research cycle to identify knowledge needs, develop data collection products, and adapt identified knowledge to a local context. Despite increasing recognition of the importance of involving consumers and the community in health research, there is little empirical evidence on the extent, impact and outcomes of their involvement in paediatric disability research. It has further been recommended that consumer involvement be evaluated as a complex intervention, identifying what works, for whom and in what circumstances. As such, Chapter Seven aimed to describe the impact and outcomes of consumer involvement in the research project, and identify the processes and contexts that fostered these. The results of this chapter have considerable implications for researchers and key stakeholders and their involvement in research, describing pertinent processes and contexts that enable meaningful engagement of consumers, enhance the quality of research, and accelerate knowledge translation.
7.1 Abstract

Purpose: To describe the impact, outcomes, processes and context of involving consumers and the community in childhood disability research.

Method: A steering group comprising nine stakeholders (an adolescent with a disability, parents of children with a disability, a paediatrician, allied health professionals, representatives from non-government organisations, and a policy maker), attended five meetings over 24 months. Stakeholders were involved in varying stages of the research cycle for each study in the project. Scrutiny of relevant documentation within a descriptive case study design was used to identify context, processes, impacts, and outcomes. Framework analysis using the Guidance for Reporting Involvement of Patients and Public checklist synthesised all data.

Results: Stakeholders contributed to, and advised the research team, on one scoping review and five original studies. Consumer involvement had a broad, positive impact on all stages of the research process. This study identified three key processes (organisational, operational, and dissemination) whereby the impact of consumer involvement evolved. A context that was values-based, membership-centred, and activity-based promoted stakeholder involvement and subsequent impact.

Conclusions: This study reports evidence of processes and contexts of consumer involvement that can enhance the quality of research, ensure its relevance to the target group, and accelerate knowledge translation.
7.2 INTRODUCTION

Consumer and community involvement (or patient and public involvement) in research describes an active relationship between researchers and the community, whereby research is carried out with or by consumers, rather than consumers being research participants [1]. Consumer involvement in research is viewed on a continuum ranging from consultation, to collaboration, to user control, indicating a low to a high level of involvement, respectively [2]. Globally, there has been an increasing recognition of the importance of involving consumers and the community in health research [3, 4]. In Australia, The Statement on Consumer and Community Participation in Health and Medical Research was developed by the National Health and Medical Research Council (NHMRC) and Consumer Health Forum (CHF) in recognition of the contribution that consumers can make to research, and their right to participate in research [5]. Rationales for involving consumers in research cited in the literature are typically underpinned by stances relating to methodology (improving the quality and impact of research), morality (i.e. it is the right of a tax-paying citizen), and political value (policy directives and funding and governance requirements to enhance translation of outcomes) [6]. Subsequently, it is a directive in many countries that consumers can and should be involved in all stages of health research [5, 7, 8].

Despite these clear drivers, there is little empirical evidence on the extent, impact and outcomes of consumer involvement in research [9]. A recent systematic review has criticised the limited evidence base for poor quality of reporting, with the depth of information too brief to provide a full understanding of impact [10]. While the state of the evidence is reflective of its developing nature, it is an area where, until recently, little guidance on reporting impacts and outcomes has existed [10]. Through collaboration with consumers and the community, Brett et al. [10] identified the importance of context and process in the interpretation of consumer involvement impact. From this, The Guidance for Reporting Involvement of Patients and Public (GRIPP) checklist was developed, an attempt to regulate and enhance the quality of consumer involvement reporting to strengthen the future evidence base [11]. The checklist considers consumer involvement as a complex intervention [12], where impact needs to be evaluated alongside broader factors in order to identify what works, for whom, and in what circumstances [11]. By providing detail about processes and context, researcher experience can provide a source of insight to influence others, in the same way that consumer experience assists in shaping research [13].

In disability research, the research process is still largely governed by researchers, and consumers are rarely meaningfully involved in all research stages [14]. This study describes the involvement of
consumers and key stakeholders in a project that is adapting an existing evidence-based intervention that enables children and youth with disabilities to participate in physical activity. The project was constructed based on the Medical Research Council’s complex intervention framework [12] and the Canadian Institute of Health Research Knowledge-To-Action Cycle [15], to facilitate the development of a context-specific intervention that is relevant, sustainable and acceptable to its users. A key recommendation across both frameworks is engaging consumers and the community throughout this process, to identify knowledge needs, and adapt identified knowledge to a local context to effectively tailor and implement the intervention [12, 15]. Accordingly, a consumer-driven steering group was engaged to guide and contribute to all studies within the project, to ensure its relevance to the needs of the target group, and to foster knowledge translation to the wider community.

There have been very few published evaluations of consumer involvement in childhood disability research [16-18]. Evaluation of meaningful consumer involvement, the impact on research, and overall outcomes is likely to lead to research that actually changes practice and improves care [14]. This article aimed to evaluate the impact, outcomes, processes and context of consumer involvement on all of the studies, and the research project as a whole. In this article, the term ‘stakeholders’ refers to children, parents, health professionals, service providers and policy makers involved in the design and conduct of the studies in the research project. The term ‘researchers’ refers to members of the research team involved in the design and conduct of the studies. The term ‘consumer involvement’ describes the act of stakeholders directing and/or informing the research. ‘Impact’ describes the effect of the group on each stage of the research, and ‘outcomes’ describe the product of this impact and involvement [11]. ‘Context’ refers to the conditions required for consumer involvement to have an impact, and ‘processes’ describe actions or steps that facilitated impact [11].

7.3 METHODS

7.3.1 DESIGN

A descriptive case study approach using scrutiny of relevant documentation (meeting minutes, meeting presentations, researcher journals, ethics applications, conference abstracts, and documented changes to research design, methods, interpretation and dissemination) was used to understand the context, processes and any impact of consumer involvement in the five studies. This design has previously been applied for evaluations of consumer involvement advising multiple studies [19]. As the aim was to also consider the project as a whole, data were examined both within and across studies.
to evaluate the involvement and its impact, and elucidate any overarching approaches which led to or hindered any impact on the research.

Ethics approval for this study was obtained from the Princess Margaret Hospital Human Research Ethics Committee (2013099), The University of Western Australia (RA/4/1/6556), and Curtin University (HRE2016-0387).

7.3.2 RESEARCHER TRAINING

Three researchers (CW, NG, CE) participated in a one day training course specifically designed to develop knowledge and skills required for the implementation of consumer and community involvement in research [20, 21]. Researchers were trained with regards to deciding which stakeholders to involve in research, the type of involvement, how to recruit stakeholders, and the resources that would be required by stakeholders and researchers for the consumer involvement process. Following this training, it was determined that consumer involvement would be implemented as a steering group [22], at the level of collaboration [2], for the duration of the project timeline.

7.3.3 STAKEHOLDERS

7.3.3.1 INCLUSION CRITERIA AND RECRUITMENT

The inclusion criteria for stakeholder involvement was informed by McKenzie and Haines’ Stakeholder Wheel [22]. Using this framework, we identified groups in the community that would likely have perspectives to contribute, and may want to be involved in the project. These included: children and adolescents with a disability, parents of children with a disability, medical specialists, allied health professionals, non-government organisations (NGOs), and policy makers associated with childhood disability.

Stakeholders in the steering group were recruited through letters of invitation, expressions of interest and identification of consumer representatives with potential interest in the research project. Recruitment was undertaken by the first author (CW). To recruit parents of children with a disability, every third family on a hospital patient database was sent a letter of invitation. Allied health professionals and representatives from NGO’s were recruited through advertisements delivered through professional networks asking for expressions of interest. An adolescent with a disability, a policy maker, and a paediatrician were purposefully selected and sent individual letters inviting them.
to be a part of the group. All recruitment communication included a plain language summary of the 
background and aims of the research project, and information detailing the role of the stakeholders, 
requirements for their participation (e.g. being able to work in a group environment) and an outline 
of their expected commitment to the project (two years). It was detailed from the outset that consumer 
involvement in the research would not be renumerated, however costs related to expenses such as 
parking would be covered.

7.3.3.2 Participating stakeholders

Nine stakeholders accepted invitations to participate in the steering group. All purposefully sampled 
stakeholders accepted invitations to participate. Two parents, two allied health professionals, and two 
representatives from community-based disability services expressed interest in being a part of the 
group. Given these numbers, no secondary application process was required and all candidates were 
accepted to be a part of the group. While free training was offered to all stakeholders through the 
Consumer and Community Health Research Network [23], all declined the invitation. Demographic 
information of all participants is detailed in Table 7.1.

Table 7.1 Stakeholder demographics

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Gender</th>
<th>Occupation</th>
<th>Meetings attended (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>High school student</td>
<td>5</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>Parent</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>Parent/accounts manager at IT firm</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>Paediatrician (hospital)</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>Policy maker</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>M</td>
<td>Physiotherapist (hospital/community)</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>Physiotherapist (community)</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>CEO of disability NGO</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>M</td>
<td>Coordinator of Community and Social Support Programs in a rehabilitation centre</td>
<td>5</td>
</tr>
</tbody>
</table>

M, male; F, Female; CEO, Chief Executive Officer; NGO, Non-government Organisation.

7.3.4 Procedure

7.3.4.1 Meeting set-up and processes

The first author (CW) was responsible for the organisation and implementation of all meetings. Email 
was the main form of communication between stakeholders and the chairperson (CW), with the 
exception of one stakeholder who elected to be contacted primarily by phone. To determine a time
for stakeholders to meet, parents and the student were contacted to find the most suitable time. Following this, their elected time was forwarded on to all other stakeholders who had expressed interest in the group.

The first author (CW) was responsible for developing the initial draft Terms of Reference for the steering group. The Steering Group Terms of Reference were underpinned by the NHMRC and CHF’s Model Framework for Consumer and Community Participation in Health and Medical Research [24]. The Terms of Reference outlined the role of the steering group, accountability (including acknowledgement of the group in any subsequent publications), and membership specifics. The steering group committed to:

1. Act as a liaison between community members, consumer organisations and the research team.
2. Advocate to the research team on behalf of consumers and the community
3. Provide feedback on the development of each stage of the research project
4. Provide advice on how to ensure consumer and community representatives can be recruited to participate in other councils established by the research team/department
5. Provide evaluation and feedback of consumer and community participation in research

Meetings were called only when the research project was at a stage that required the input and/or direction of consumers (typically at the development and analysis stage of each study). Stakeholders were given at least two months advance notice to the date of the next meeting. An agenda was sent to stakeholders one week prior to each meeting, and minutes of the meetings sent no later than one week post-meetings. While there was no remuneration in any form for stakeholders or facilitators of the group (CW, SG), there was also no cost associated with their involvement, other than their time.

7.3.4.2 CLEAR DESCRIPTION OF ALL INVOLVEMENT ACTIVITY

A total of five meetings were held over 24 months, with a range of 6-10 attendees. All meetings were held in the same board room at The University of Western Australia. Other than the chairperson, one additional member from the research team (SG) was present during meetings to assist in facilitating discussions and document field notes. With informed consent from stakeholders, all meetings were audio recorded to enable the chairperson (CW) to accurately document all proceedings.

At the beginning of all meetings, discussions were held regarding the value of involving consumers in research and why they were needed for the project. Additionally, reminders of the group ‘rules’ for effective meetings (e.g. confidentiality) were discussed briefly. Meetings were typically structured in
two parts. Part one involved the delivery of results from a study the steering group had previously been involved in, for (i) consultation in data analysis and interpretation, (ii) validation (or invalidation) of results against their lived experience, and/or (iii) the dissemination of research outcomes to individuals who can directly benefit from, or further disseminate, the outcomes. Part two of meetings involved the active engagement of the group in developing the aims of a study, and/or developing, refining or piloting tools to be used for data collection in upcoming studies. Details of the role of the steering group in each meeting are described in Table 7.2. Details of stakeholder involvement across all research stages and studies can be seen in Table 7.3.
Table 7.2 Details of activities of the steering group in each meeting

<table>
<thead>
<tr>
<th>Meeting number</th>
<th>Description of studies for steering group consultation</th>
<th>Role of the steering group</th>
</tr>
</thead>
</table>
| 1              | **Study 1**: To determine the barriers and facilitators of participation in community activities for children with an acquired brain injury (ABI). Method: Using Q-method, parents of children with an ABI would be asked to sort a set of predetermined statements onto a normally distributed grid ranked from strongly agree, to strongly disagree. The Q-concourse for the study was developed through a systematic review that identified barriers and facilitators impacting on participation of Australian children and youth with neurological impairments, and preliminary data from a scoping review identifying elements that contribute to meaningful participation for children and youth with disabilities.  

The steering group was asked to complete the Q-sort individually, and provide feedback regarding:  
- The wording of statements  
- The barriers and facilitators covered in the statements  
- The experience of completing the sorting task |}
| 2              | **Scoping review**: To identify the elements of community programs and activities that create meaningful participation experiences for children and youth with disabilities.  

The steering group was presented preliminary results (qualitative themes) identified from the review, and asked to:  
- Validate/invalidate the results against their lived experiences  
- Advise the researchers of the inclusion/exclusion of a theme (‘the opportunity to participate’) i.e. does this theme answer the research question or is this a precursor for participation, and why? |}
|                | **Study 2, 3, & 4**: To identify the active ingredients of a physical activity participation intervention for children and youth with disabilities. Methods: The primary researcher would spend 15 weeks at a rehabilitation centre in Norway. Ethnographic fieldwork would involve semi-structured interviews and participant observation.  

The steering group was asked to assist in the development of interview questions that would identify the active ingredients of the participation intervention, according to:  
- Children  
- Parents  
- Staff at the Centre  
- Service providers in the community that visit the Centre |
The group was informed that questions would be organised into an interview guide that would be used to direct and prompt interviews with each participant group.

<table>
<thead>
<tr>
<th>3</th>
<th><strong>Study 1:</strong> Final results and the contribution of the steering group to the results presented to the steering group, and dissemination strategies discussed.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The steering group was asked to interpret the results, facilitated by the following prompts:</td>
</tr>
<tr>
<td></td>
<td>- Expected/unexpected</td>
</tr>
<tr>
<td></td>
<td>- Reflective of their lived experiences</td>
</tr>
<tr>
<td></td>
<td>- How can we use this data?</td>
</tr>
<tr>
<td></td>
<td>- Ideas for future research</td>
</tr>
</tbody>
</table>

**Scoping review:** Final results and the impact of the steering group on the results was presented to the steering group, and dissemination strategies were discussed.

<table>
<thead>
<tr>
<th>4</th>
<th><strong>Study 5:</strong> To identify services in the Western Australian community that facilitate the participation of children and youth with disabilities in community leisure activities.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Methods: A survey will be developed to identify services in the Perth metropolitan area, based on a community mapping process. This data will be used to develop application software (App) that parents/service providers can access to help facilitate community leisure participation for children and youth.</td>
</tr>
<tr>
<td></td>
<td>The steering group was asked to assist in the development of the survey, consulting in regards to:</td>
</tr>
<tr>
<td></td>
<td>- What would you want the App to tell you?</td>
</tr>
<tr>
<td></td>
<td>- What information would we need to obtain from communities?</td>
</tr>
<tr>
<td></td>
<td>- What questions need to be in the survey?</td>
</tr>
<tr>
<td></td>
<td>- Other comments relating to the survey</td>
</tr>
</tbody>
</table>

|    | The steering group was asked to pilot the survey and provide feedback regarding:  |
|    |  - Content  |
|    |  - Language  |
|    | The steering group was asked to develop vignettes to be included as a part of the survey  |

| 4  | **Study 5:** Following the feedback from the steering group, the researchers adapted an existing survey obtained from the literature [25]. |

The steering group was asked to pilot the survey and provide feedback regarding:

- Content
- Language

The steering group was asked to develop vignettes to be included as a part of the survey.
Study 2, 3, & 4: Results from data collected in Norway presented to the steering group.

The steering group was asked to interpret the researcher analysed results:
- In relation to their lived experiences
- Identify any gaps in the results
- Consider how context and the environment may influence the operation of active ingredients

The steering group was asked to link the data, and consider:
- How the active ingredients could be incorporated into the design of an intervention/program
- How the active ingredients could be applied to an Australian context

Table 7.3 Details of stakeholder involvement in each study

<table>
<thead>
<tr>
<th>Study</th>
<th>Meeting number</th>
<th>Developing aims</th>
<th>Developing methods/data collection tools</th>
<th>Data analysis and/or interpretation</th>
<th>Dissemination</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scoping review</td>
<td>3</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Study 1</td>
<td>1, 3</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Study 2</td>
<td>2, 5</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Study 3</td>
<td>2, 5</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Study 4</td>
<td>2, 5</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Study 5</td>
<td>4</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>
7.3.4.3 METHODS TO CAPTURE IMPACT

MEETING MINUTES

With informed consent from the steering group, each meeting was audio recorded and transcribed verbatim. The chairperson (CW) developed comprehensive minutes from the transcriptions of the meetings. The minutes contained detailed, plain language summaries of all events and discussions from the meeting, of which were verified at the following meeting. This included (but varied between meetings); (i) details of studies the group had been involved in during the previous meeting (including results and conclusions, and impact of the steering group on that study), (ii) discussions relating to data presented to the steering group for their interpretation and/or validation of lived experience, (iii) description of contributions of the steering group in the preparation of an upcoming study, and (iv), a timeline for the next stage of data collection and analysis. Other pertinent discussion points (e.g. preferences for future research) were included in the minutes if they arose.

FIELD NOTES AND JOURNALS

The additional researcher (SG) present during meetings recorded field notes regarding stakeholder behaviours, reactions and contributions during discussions. Furthermore, the chairperson (CW) kept a journal that was completed immediately after each meeting, documenting reflections and preliminary thoughts in relation to the perceived impact of the steering group on the research.

RESEARCH STUDY DOCUMENTS

All documents relevant to the scoping review and five original studies, including ethics applications, project notes and memos, conference abstracts, publications, and any reports or descriptions of the studies were scrutinized. Documents and data collection tools from each study were reviewed to compare (and if possible, calculate) changes made by the steering group, and formulate qualitative descriptions of the impact (positive or negative) on the research design, methods, results, and/or dissemination.

7.3.5 DATA ANALYSIS

NVivo (QSR International Pty. Ltd., 2015) software was used for handling all data. All relevant data were extracted from the written documents and anonymised. Meeting minutes, field notes, journals and documents were initially categorised into case studies, so to align with the scoping review and research studies 1-5. All documents were analysed using direct content analysis [26] and the reporting
framework of the GRIPP checklist [11]. Framework analysis is particularly suited to cross-sectional
descriptive data, enabling different aspects of the phenomena under investigation to be captured [27].
Data were coded according to the context, process, impact, or outcome domains of the framework.
Data were coded as context if it described conditions required for consumer involvement to have an
impact [11]. Processes were coded as data that described a series of actions or steps taken to facilitate
impact [11]. Data were coded as impact if it described a marked effect or influence on any aspect of
the research [11]. Outcomes were coded as data that described the final result or product of
involvement [11]. After applying the GRIPP coding framework, codes within each domain were
reviewed to merge similar codes and synthesise the impact and outcomes within each study and on
the overall project, and the contexts and processes associated with these. The first author (CW) coded
all data, and a second author (SG) reviewed and checked the coding with no disagreement.

7.3.6 Trustworthiness

Several measures were employed to ensure trustworthiness [28]. Triangulation of data collection
methods, member checking with stakeholders, and the researcher documenting reflections in a journal
enhanced the credibility of the research. Purposive sampling of stakeholders and the thick descriptive
data enhances transferability, and using a variety of data sources contributes to confirmability [28].
Further, framework analysis enabled in depth exploration of the data while simultaneously
maintaining a transparent audit trail, which enhances the rigour of the analytical processes and the
credibility and dependability of the findings [27].

7.4 Results

7.4.1 Impact and Outcomes of Consumer Involvement on the Research

The steering group contributed to, and advised the research team, on one scoping review and five
original studies. Sixty documents were analysed and data were categorised according to study
number. The impact and outcome of the Steering Group on each study is described in Table 7.4. The
impact and outcomes of the Steering group as a whole can be seen in Table 7.5.
Table 7.4 Impact and outcomes of the steering group on each study of the research project

<table>
<thead>
<tr>
<th>Study</th>
<th>Results from collaboration</th>
<th>Impact</th>
<th>Outcome</th>
</tr>
</thead>
</table>
| Review | **Data analysis:**  
The steering group was overwhelmingly in support of the inclusion of ‘the opportunity to participate’ as a major theme contributing to meaningful participation. The group emphasised that the lack of available participation options in the community meant that when they were presented with these opportunities, they were highly valued by children and parents, and this contributed significantly to the overall meaning of the experience for the child and their family. | **Data analysis:**  
Include the theme, ‘the opportunity to participate’ in the results to answer the research question. | The results, including a description of the involvement and impact of the steering group, have been published [29]. |
| | **Data interpretation:**  
- Elements contributing to meaningful participation apply to all children, not just children with disabilities.  
- The elements are all important, and are an accurate portrayal of children’s experiences.  
- Having friends and having fun were reinforced as the most critical of the elements.  
- Experiencing these elements may translate into more positive outcomes in different settings and throughout the lifespan. | **Data interpretation:**  
Validation of results against lived experiences. | Enhances the generalisability of the outcomes of the review (qualitative meta-synthesis). |
| 1 | **Developing data collection tools:**  
- Too many statements (~25 minutes to complete the sort).  
- Too many statements that fit on the ‘agree’ side.  
- There should be positively and negatively worded statements. | **Developing data collection tools:**  
62% of the statements were changed:  
- Statements were reduced from 50 to 37.  
- Positive, negative, and neutral statements equalised (from 21/5/11 to 13/13/11). | Mean data collection time per parent in a busy clinic environment was 13 minutes.  
Sample reported high relevancy of the statements to their actual lived experiences. |
• There are no statements describing motivation, siblings or travel time.
• Unsure about what is a ‘community activity’ and what this can include.
• Word changes within statements.
• Described the q-sort as a reflective process that allows a parent to recognise what the deficits are, but at the same time recognise what you/the family/child in mind can aspire to.

Three new statements were added
• Script to introduce tool to study participants was re-written, inclusive of definition of community participation.

Sample reported high satisfaction of their final sort as an accurate representation of their viewpoint.

“I felt like I could relate to every single statement as I know we have experienced each one of those” – study participant

Data interpretation:
• The increase in age corresponding with the decrease in perceived ability to participate was confirmed as highly reflective of community participation experiences of stakeholders.
• The age group of children facing barriers was reflective of transition life stages.
• Three months post injury was perceived by stakeholders as very early to be considering community participation. Suggestion that discussions early post-injury (3 months) surrounding community participation may not be a negative thing. Planting the seed of ‘possibility’ could in fact be a positive step in the recovery process for parents.

Data analysis:
35/37 statements significantly aligned with/defined a viewpoint in the factor analysis.

Data interpretation
Validation of results against lived experiences.

The results, including a description of the involvement and impact of the steering group, have been published [30].

Validation of results as accurately reflecting the group’s experiences enhances the generalisability of the outcomes of the study.

2, 3 & 4 Developing data collection tools: Interview questions (k) were developed for:
• Children (k=22)
• Parents (k=18)
• Staff (k=26)
• Service providers visiting the centre (k=10)

Developing data collection tools:
When compared to researcher developed guides, new topics and/or questions were added (total change of 20-30% per guide)
• Children (k=4)
• Parents (k=6)
• Staff (k=5)

Parents were highly responsive to questions during interviews, willing to answer and elaborate on all questions and often very emotional.

Children offered the most information to the question, ‘would you recommend it to other kids (and
For questions that covered similar topics, these were re-worded to adopt the language suggested by the steering group.

For children with disabilities, we need to help them find the confidence to find their mountain, their place where they feel like they can and are doing the stuff that all the other kids do” – stakeholder

Identification of gaps in the results:
- No data to indicate parent mental health. This may/may not affect child and parent outcomes

Discussed further in data linkage, Table 7.5.

\textit{Developing aims and study focus:}

\begin{itemize}
\item What recreation and leisure services are there in the community?
\item Do organisations have experience in providing recreation activities to children with disabilities? Why/why not?
\item Is the organisation willing to facilitate the special needs of a child with a disability? Why/why not?
\end{itemize}

Proposed study sample:

Results from this study will directly fulfil a consumer-identified need, using a consumer developed data collection tool.

Results from this study have informed the development of application software (knowledge product).
- Send the survey to club presidents/organisation directors.
- Invite these positions to complete the survey, or delegate to other staff/volunteers that are in an experiential position to provide answers

**Developing data collection tools:**
- There has to be an educative role in the survey. People’s knowledge of disability is limited, so specific examples of the cognitive, behavioural and/or physical implications of disability within specific recreation settings may be required to ensure the survey is filled out correctly.
- Written in plain language
- Include questions about service provision, barriers and facilitators, and attitudes, for disabilities generally

activity-based recreation and leisure activities in the community. Additionally, this study aims to identify the barriers and facilitators associated with this service provision.

**Developing data collection tools:**
Four vignettes were written by the steering group that are read before services complete questions relating to disability. Topics in the survey include:
- Characteristics of the organisation
- Provision of recreation activities and associated services
- Inclusion of children with disabilities
- Level of specialisation among community-based personnel
- Perceived barriers and facilitators to the provision of services
- Attitudes associated with disability

Results from this study, including the launch of the app, will be disseminated in a community forum, to encourage collaboration between service providers (steering group suggestion).
Table 7.5 Impact and outcomes on the overall project

<table>
<thead>
<tr>
<th>The overall research project</th>
<th>Results from collaboration</th>
<th>Impact</th>
<th>Outcome</th>
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<tr>
<td></td>
<td>Data linkage:</td>
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<td>Key points:</td>
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<td></td>
<td>• The importance of obtaining both child and parent perspectives. For example, role models were identified as important to the children in the scoping review, but parents completing the q-sort did not identify role models as a defining factor.</td>
<td>Data linkage: Development of clinical recommendations and preliminary design of an ‘Australian’ intervention, incorporating the findings from all studies, to enable children with disabilities to participate in community leisure activities, and in physical activity.</td>
<td>Connecting communities: “You [stakeholder] are the reason that [my child with a disability] goes to [school]...you are such an inspiration to so many people, we wanted [my child with a disability] to be able to have you as a role model” – stakeholder</td>
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<td></td>
<td>• The importance of friendships in facilitating participation. This was identified across the scoping review, the q-sort, and the studies 2, 3 &amp; 4, completed in Norway.</td>
<td></td>
<td>Fostered linkages between research institutions and the wider community.</td>
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<td>Incorporating data into design of intervention:</td>
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<td></td>
<td>• The primary requirement is to have a vision, and ensure this vision is shared throughout the intervention/service.</td>
<td></td>
<td>Addressed the goals of key stakeholders in the health sector that have a strong overlap.</td>
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<td></td>
<td>• An individualised, goal directed approach within a group-based design is essential.</td>
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<td>• Create a ‘safe’ place, to allow children to try new things, and find activities they enjoy.</td>
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<td>Knowledge translation: Communities were empowered to respond to their needs (e.g. development of an all-abilities Australian Rules football team)</td>
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<td></td>
<td>• Support networks for parents, and ensure a place for siblings.</td>
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<td></td>
<td>• Incorporating/offering interventions for parent mental health/well-being should also be a primary consideration.</td>
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<td></td>
<td>• Focus on community capacity building: not reinventing the wheel, but engaging resources that already exist and adapting them if necessary.</td>
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<td></td>
<td>Considerations for an Australian context:</td>
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<td></td>
<td>• Activities need to be relevant and meaningful to Australian children. Activities need to go beyond just team sports, and like Norway, include individual and family activities like going on a hike in the bush, playing at the beach or doing yoga etc.</td>
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<td></td>
<td>• Coordinate with local services and utilise local resources (gave local examples).</td>
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<td></td>
<td>• Connect children and families living in suburbs close to each other.</td>
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<td></td>
<td>• Consider governance in Australia.</td>
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</table>
7.4.2 CONTEXT

Three themes relating to context evolved from the analysis. These themes describe the conditions that were required for the group to have an impact on the research.

7.4.2.1 VALUES-BASED

A context that recognised and embodied the values of the consumer, and the principles of the NHMRC Statement on Consumer and Community Participation [5], was required for the group to have an impact. As consumers did not undergo training, it was imperative that they understood why consumers were valuable for research and why they were needed to guide and direct this research. Equally, it was essential that the researchers had an understanding of the expectations of the consumers, and openly acknowledged their own accountability to the consumers (in the meetings and in the Terms of Reference). This context was established in the first communications with stakeholders (through written documents), and was reinforced in all meetings (through verbal and visual communication).

7.4.2.2 MEMBERSHIP

Facilitating a context of membership influenced the consumers’ impact on the research. Stakeholders were united by a mutual experiences, and were working together to achieve a common goal. Routine operational processes of having each meeting with the same people, at the same place, created an environment of trust and unity whereby stakeholders could feel comfortable in sharing information. Strategies for an ‘effective meeting’ (including confidentiality) were presented to the group at the beginning of each meeting to facilitate this context. As more meetings occurred, more personal stories and life experiences were shared, contributing to data collection tool development (e.g. q-sort, interview guides) or validation of results.

7.4.2.3 ACTIVITY-BASED

Typically, the consumer group was perceived by the chairperson and research team to have greater understanding (and therefore impact) of their advisory roles when participating in an activity (e.g. piloting the measurement tools, developing interview questions, writing vignettes) rather than solely in a discussion (e.g. commenting on the model in the scoping review). Whilst the steering group actively engaged in discussions relating to the interpretation of results in relation to their lived
experience, the greatest influence of the steering group at all stages of the research cycle was during task-based consultations.

7.4.3 PROCESSES

Three processes were identified that facilitated the impact of consumer involvement.

7.4.3.1 ORGANISATIONAL PROCESSES

A number of organisational processes that occurred both prior to the groups’ formation, and prior to each meeting, affected consumer impact on the research. Ethical approval was obtained to enable the evaluation of the impact of consumers on the research, and to understand the impact of being involved in research on consumers. This enabled the research team to document impact and outcomes, and disseminate these within publications generated from each study in the research project. Additionally, both purposive sampling and researcher training likely affected impacts; the group was made up of individuals for whom the research was relevant and who could make meaningful contributions, and researchers had the skills and knowledge to ensure the effectiveness of this engagement for consumers, the research and the community.

Minor organisational processes such as distributing a meeting agenda to stakeholders in the week prior to meetings, and developing and circulating comprehensive minutes following the meetings, may have affected their impact on the research. The agenda encouraged stakeholders to consider topics of the upcoming meeting, and also offered them the opportunity to add items to the agenda. Similarly, the minutes allowed stakeholders to reflect on the outcomes of each meeting, have a source that may assist in their dissemination of knowledge, and to provide documentation of their contributions, impact, and outcomes.

These organisational processes took a significant amount of time for the chairperson to carry out. However, based on the impact the consumers were having on the research, the research team viewed these as an essential component of the overall process.

7.4.3.2 OPERATIONAL PROCESSES

Processes occurring within consultations affected impact and outcomes. Meetings were structured around a PowerPoint presentation, of which visual and photographic material and lay language
largely assisted stakeholder understanding of studies and their role. Furthermore, it enabled clear and simple instructions to be available to the group whilst completing the task, of particular use to the stakeholder with a disability. Furthermore, the researcher based meetings on the assumption that stakeholders did not have the depth of knowledge of each study, or memory of the events of the previous meeting, that the primary researcher held. As such, time was allocated in each meeting to review background, aims, and any previous contributions. This assisted in ‘setting the scene’ for quality engagement in the meetings focus and/or task.

Ensuring transparency of the broader research process was pivotal for consumer buy-in. This was applied in a number of ways including; updates on data collection progress for concurrent studies, openly discussing challenges occurring in the project that required reporting (e.g. delays with ethics approval), and a ‘where to from here’ discussion at the end of each meeting, to communicate to consumers the activities of the researcher between meetings. Finally, the chairperson kept a reflective journal that was completed following each meeting. This described actions of the chairperson that went well, aspects of the meeting that could be improved on, and any reflections relating to the outcomes of implemented recommendations from previous meetings. This process of continuous quality improvement helped to ensure an optimal context was in place for consumers to have the greatest opportunity for impact on the research.

7.4.3.3 Dissemination processes

Dissemination of the results of studies using lay language summaries to consumers enabled their involvement in the full research cycle. Furthermore, dissemination of the impact of the consumers on each study gave the group a tangible understanding of the impact and outcomes of their role in the research. Instances where it was possible to quantify their involvement (e.g. percentage changes to data collection tools such as the q-sort) facilitated a greater understanding by consumers of their contribution. The process and impact of involving the steering group in research was presented at a number of conferences [31, 32], of which the group contributed to. This was an attempt by the research team to further reiterate the groups’ value to the project, to encourage their ongoing consultation and probable impact.

7.5 Discussion

The outcomes of this study demonstrate the broad, positive impact of involving a consumer-driven steering group in childhood disability research. Conceptualising consumer involvement using key
components of the GRIPP checklist enabled the identification of what works, for whom, why and in what circumstances. Key organisational, operational and dissemination processes operationalised in a context that was values-based, membership-centred, and activity-based promoted stakeholder involvement, and subsequent research impact and outcomes.

The involvement of stakeholders in the research occurred most frequently in method development and data analysis stages of the project, and this is subsequently where the greatest impact was observed. Consumer involvement in the development of data collection tools identified lines of inquiry not previously considered by the researchers, and enhanced the relevance of the instruments. Similarly, involving stakeholders in the analysis process often broadened the interpretation of data, and identified the aspects of research that had the most relevance to consumers. Although these impacts have been documented previously in health research [33], there is limited evidence of this in paediatric disability sector. While this may indicate a significant gap in the research process of this field, it may be that consumer involvement in a study is not being reported in peer-reviewed journals [10, 34]. A review of studies from selected health research journals identified that while only six out of the included 200 papers reported consumer involvement, 40% of these authors declared in a follow-up questionnaire that they had in fact involved consumers in the research process [34]. The process, impact and outcomes of consumer involvement in each study of the research project has been (and will be) included in all associated publications, both to encourage researchers to incorporate consumer involvement as a part of their research process, and demonstrate strategies in which barriers associated with publication can be overcome.

This study identified key procedures and conditions of consumer involvement that facilitated impact on the research. Organisational, operational and dissemination processes were imperative to this. Specifically, researcher training was critical to ensuring the effectiveness of this engagement for consumers, the research and the community. This is consistent with evidence that suggests the better the training, planning and procedures that are put in place for consumer involvement, the greater the potential for beneficial impact [10, 21]. Similarly, the literature describes an increased likelihood of impact with greater trust and respect that stakeholders and researchers have with each other [10, 35]. This was observed in this study, with the theme of ‘membership’ proposed as a key contextual factor that facilitated impact. This may be particularly salient for engaging consumers in paediatric disability research, whereby consultations may evoke sensitive or emotionally challenging topics for stakeholders. This may also be why task-based consultation activities were so effective, conceivably creating a context where stakeholders could feel comfortable contributing their perspectives and experiences, without pressure of formal discussion about sensitive and emotional topics.
Outcomes of this evaluation suggest that meaningful stakeholder engagement can lead to accelerated dissemination and translation of research findings. One of the stakeholders was a part of a local Australian Rules football club, who (following their involvement in multiple meetings) assisted in the development of an all-abilities football team for children. The development of this team directly addressed barriers to community participation identified in study 1, embodied many of the ‘active ingredients’ identified in studies 2-4, and created a program where children with disabilities were able to participate in physical activity in the community – the ultimate goal of the research project. In this sense, stakeholders adopted the role of knowledge brokers, promoting the integration of the best available evidence to tailor programs specific to the needs of the community [36]. Involving consumers in research ensured that our endeavours not only remained reflective of the needs of the community, but the community was also empowered to respond to these needs.

This study had a number of methodological strengths. Previous research demonstrates that individuals with disabilities and their caregivers are more frequently engaged in rehabilitation research compared to other stakeholder groups [14]. As the goal of our overall project (like others) was to fill a gap in service delivery, decision-makers, health care professionals, and community group representatives were also involved in the research process in an attempt to ensure project feasibility, outcomes and sustainability. Additionally, these same stakeholders were involved throughout the research cycle of each study in the project. While it has been suggested that consumer involvement may have a more positive impact when service users are involved throughout the study [33], outcomes of this research suggest that this impact is also observed when stakeholders are involved in multiple studies. This evaluation process was able to capture how the research projects evolved, and likewise whether the participants’ roles changed over time. Whilst the stage of the research of which consumers had the greatest impact varied between studies, the nature of their involvement (collaboration) remained the same throughout their engagement in the project. This study adds further support to the idea that ongoing partnerships between stakeholders and researchers can lead to accelerated knowledge translation [37].

7.5.1 Implications

Outcomes of this evaluation suggests that the impact of consumer involvement was positive, both in terms of the research process and the project outcomes. This aligns with current systematic reviews documenting the impact of consumer involvement, whereby the majority of impact on the research is reported as beneficial [10, 33]. In this study, the only negative impact was the time-related aspects of
planning, gaining access to, and managing stakeholder involvement in the research for the academic researchers. While this did not impact the overall project timeline, researchers attempting to engage stakeholders in research should be aware of this.

As most studies in the research project were exploratory in nature, it could be argued that these methods provided a wider scope for involvement. However, consumer involvement has demonstrated efficacy in various health research fields alongside randomised control trials and systematic reviews [38, 39]. In addition, stakeholders can assist to identify gaps in research for future studies to address and can become advocates of the research findings to foster a wide dissemination of results [33].

7.5.2 LIMITATIONS

There are some limitations associated with this research. Not all stakeholders were present at all meetings, which may have limited our understanding of the perspectives of the part of the community they were representing. Those that experienced the most difficulties attending meetings were allied health professionals. Of note, the stakeholders of whom the meeting times were specifically accommodated for (i.e. parents and an adolescent student) were at all meetings. Secondly, the lack of validated, objective measurement of the impact of consumer involvement in the research project means that the ‘success’ of this could only be determined subjectively by the research team. Finally, although the GRIPP checklist informed the write up of the impact of consumer involvement, this study did not specifically test any theoretical frameworks as recommended.

7.6 CONCLUSION

This evaluation study demonstrates the broad and positive impact of involving consumers and the community in childhood disability research. Consumer involvement had an impact on varying stages of the research process across multiple studies. Conceptualising consumer involvement as what works, for whom, why and in what circumstances may encourage researchers in this field to adopt similar methods, and report on impacts and outcomes within their publications. This study reports clear evidence that consumer involvement can enhance the quality of research, ensure the relevance of results to the target group, and accelerate knowledge translation.

ACKNOWLEDGEMENTS
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DECLARATIONS

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7.7 References


Chapter Eight

SUMMARY OF FINDINGS AND CONCLUSIONS

8.1 SUMMARY OF FINDINGS

Linking research within the context of consumer-determined health priorities supports the development of interventions that are relevant to the needs of the target group, supporting their use and ultimate success \(^1\). When asked to describe his needs, an adolescent boy with a disability in our steering group replied:

“For children with disabilities like me, we need to know that no matter what our condition, there is still a way that we can do what we want to do in our life. To feel like we are doing the stuff that all the other kids do” — stakeholder, 17y

Talking on behalf on the 150 million children with a disability around the world \(^2\), this young man articulates what is most important to them; to participate. And yet, children and youth with disabilities continue to experience significant participation restrictions across all life settings \(^3\)-\(^5\). Currently, the literature contributing to the development and evaluation of interventions to optimise participation outcomes for children and youth with disabilities has largely been centred on identifying the evidence-base for development \(^6\)-\(^11\), and assessing feasibility and pilot testing of methods \(^12\), \(^13\). Further research is required to identify and/or develop theories, understand why effective interventions work, and develop methods that incorporate knowledge translation processes from the outset of research. This will enable the implementation of effective interventions into practice, and meaningfully address the needs of children and their families.

The overarching aim of this research was to contribute to the evolving evidence surrounding physical activity participation, to improve the design and effectiveness of interventions to enhance these outcomes for children and youth with disabilities. More specifically, this research aimed to; (i) evaluate an existing model of service that may enable participation in physical activity for children and youth with disabilities, (ii) identify the active ingredients of the intervention from the level of service delivery, (iii) understand the relationship between intervention mechanisms and context that promote outcomes for children and youth with disabilities, (iv) explore the experience of parents in the intervention, and (v), describe the impact of involving consumers and the community in the evaluation and development of complex interventions.
The research outlined above was addressed by first undertaking a scoping review, followed by five original studies, all presented as papers. Recommendations of relevant stages of the Medical Research Council (MRC) complex interventions framework\(^\text{14}\) and the Canadian Institute of Health Research (CIHR) Knowledge-To-Action Cycle\(^\text{15}\) were applied. This chapter will summarise the findings of each of these papers with respect to their hypotheses and/or guiding questions, draw conclusions based on the results, and make recommendations for clinical practice and future research to contribute towards the development of effective interventions that may improve participation in physical activity for children and youth with disabilities.

8.1.2 **CHAPTER TWO – PAPER ONE**

**ELEMENTS CONTRIBUTING TO MEANINGFUL PARTICIPATION FOR CHILDREN AND YOUTH WITH DISABILITIES: A SCOPING REVIEW**

While a large body of empirical evidence exists regarding the determinants of participation in community leisure activities of children with disabilities, there is less understanding of the experience of participation in these settings. The aim of this scoping review was to identify the components of community programs that contribute to meaningful participation experiences for children and youth with disabilities, and describe the ‘essential elements’ that should be considered when designing and implementing programs and interventions. Twenty studies met the criteria for inclusion in this review, and ten elements were identified that contributed to meaningful participation experiences in community programs and activities. The elements were interrelated, and organised as person-based, environment-focused and activity-related. This review details a conceptual understanding of the motivating and engaging factors associated with participation community-based leisure activities and programs for children and youth with disabilities, and may assist practitioners in their design of targeted interventions. As well as the centrality of friendship and social connectedness\(^\text{16}\), relationships with mentors, family and services in the wider community may need to be considered as key ingredients to attaining leisure participation goals for children and youth with disabilities. These results may be of particular significance for interventions directed at optimising physical activity participation, as accommodation in community-based programs is recognised as important for promoting long-term outcomes. Consideration of these elements in relation to enabling and sustaining participation in physical activity was explored in Chapters Three, Four, Five, and Six of this thesis.
8.1.3 Chapter Three – Paper Two

Enabling Physical Activity Participation for Children with Disabilities Following a Goal-Directed, Family-Centred Intervention

The following four chapters of this thesis are centred on the evaluation of the Local Environment Model (LEM) intervention at Beitostolen Healthsports Centre (BHC). Chapter Three addressed the first question of complex intervention evaluation, to determine whether the intervention works in everyday practice. This clinical study aimed to evaluate physical activity goal attainment, performance and satisfaction in children and youth with a disability following the goal-directed, family-centred intervention immediately post-intervention, and at 12 weeks follow-up. A secondary aim was to explore the factors influencing goal attainment in a child’s local environment following the intervention, as reported by the parent. Ninety two children with a range of disabilities participated in the study over a 12 month period. The Canadian Occupational Performance Measure (COPM) was administered to children and parents pre- and post-intervention, and at 12 weeks follow-up. Using goals from the COPM, Goal Attainment Scaling (GAS) was applied at 12 weeks follow-up to assess participation goals set post-intervention, with additional qualitative inquiry to identify factors influencing goal attainment.

The first hypothesis, that the intervention will increase perceived (parent and child) performance and satisfaction of individual physical activity participation goals post intervention and at 12 week follow up, was supported. Both child- and parent-rated performance and satisfaction scores were significantly higher at the end of the intervention, and at 12 weeks follow up, compared to baseline.

The second hypothesis, that children will attain goals relating to physical activity participation in their local community set post-intervention, was partially supported. Thirty two per cent of children achieved an expected, or greater than expected level of achievement on their GAS at 12 weeks follow-up. As discussed in Chapter Three, these results may suggest that the expected outcome on the GAS exceeded what was possible to achieve in 12 weeks. However, qualitative inquiry at 12 weeks follow up described that almost half of participants who did not attain expected outcomes were satisfied with their current progress towards their physical activity goal, or were participating in physical activities not specified on the GAS. It was subsequently suggested that measuring the multiple dimensions of participation in addition to goal attainment, and employing longer follow-up periods within the study design, may be necessary to more accurately document changes in physical activity participation in future interventions.
Following the identification of factors affecting goal attainment, environmental factors were determined to be a primary barrier to physical activity participation in local community settings. Specifically, the availability and accessibility of services are essential to enhance the sustainability of physical activity practices acquired from interventions. Results from this study can be used to inform health professionals and researchers about the effectiveness of goal-directed, family-centred interventions to optimise physical activity participation in children and youth with disabilities.

8.1.4 CHAPTER FOUR – PAPER THREE

‘CAPTURING THE MAGIC’: IDENTIFYING THE ACTIVE INGREDIENTS OF A PHYSICAL ACTIVITY PARTICIPATION INTERVENTION FOR CHILDREN AND YOUTH WITH DISABILITIES.

Given the encouraging findings from Chapter Three, it was important to answer the second question of complex intervention evaluation: how and why does the intervention work? Chapter Four, Five and Six describe these findings, from the perspectives of BHC staff and local paediatric service providers, children, and parents, respectively. Data collection for these studies was completed simultaneously, using an ethnographic approach that triangulated participant observation, interviews, and focus groups over 15 weeks in the field.

From the perspectives and practices of staff at BHC and visiting paediatric service providers, Chapter Four aimed to define the active ingredients of the intervention that facilitate physical activity participation for children and youth with disabilities. Thirteen staff from BHC and seven paediatric service providers from various regions of Norway participated in the study. Secondary coding of interview and observation data linked meaningful concepts to corresponding categories of the ICF-CY.

To answer our first question, fourteen active ingredients were identified and related to intervention design, the environment, and the effect on the individual. Whilst the active ingredients we identified in this study were not ranked in any order of importance, the group-based design was outlined by all participants as a crucial component of what happens both during and after the intervention; children and families develop strong social relationships, and create their own support network to encourage ongoing physical activity participation in their local communities. Linking the intervention to the ICF-CY verified this, highlighting the substantial role of the environment, and specifically the role of support and relationships, in enabling participation in physical activity. There were no meaning units that related to codes in the ‘body structures’ or ‘body function’ components of the ICF-CY. Thus, if
a child’s physical activity goal is participation, this should encourage health professionals to look beyond physiological and functional outcomes related to exercise, and focus on the aspects of the environment that may facilitate this.

A secondary aim of this study was to develop operational definitions of these ingredients to support implementation in other settings. These definitions emerged from the triangulation of interview and observation data, to operate as practice profiles to promote consistency across practitioners at the level of actual service delivery in any future program implementation. Understanding effective program mechanisms and their operation is a required, but often neglected, step in advancing evidence-base practice. This was explored further in Chapter Five and Six.

8.1.5 Chapter Five, Paper Four
WHAT WORKS, FOR WHOM, IN WHAT CIRCUMSTANCES, AND HOW? A REALIST EVALUATION OF A PHYSICAL ACTIVITY PARTICIPATION INTERVENTION FOR CHILDREN AND YOUTH WITH DISABILITIES.

The findings of Chapter Four described the active ingredients of the LEM as determined by professionals involved in the delivery of the intervention. Of equal importance is understanding program mechanisms from the perspectives and behaviours of those receiving the intervention. Chapter Five paper aimed to determine the association between intervention context, mechanism and child-related outcomes, from the perceptions and behaviours of the program participants. Using these results, we aimed to develop a refined program theory to inform future practice and policy surrounding similar interventions.

To address these aims and identify key combinations of context and mechanisms that trigger outcomes of the LEM, our study was based on a realist evaluation. Thirty one children with a range of disabilities and their parents (n=44) participated in the study. This study identified five mechanisms (choice, fun, friends, specialised health professionals, and time) of the LEM intervention that facilitated meaningful outcomes for children with disabilities and their parents. Whilst optimising participation in physical activity is a primary outcome of the LEM (as described in Chapter Two), this study demonstrated that outcomes of interest to children and parents extended beyond this. In particular, parents perceived the participation-based intervention to improve outcomes at the level of body functions and activity. As discussed in Chapter Five, this is a new finding and may have implications for future rehabilitation interventions, and we encourage further investigation of this hypothesis.
Also addressing our first question, Paper Four demonstrated that the interrelatedness of safe, social, learning and family contexts was required for the operation of the program mechanisms. While the role of family and social contexts in enabling participation is increasingly being documented, the need for an emotionally safe context is relatively unexplored in the literature. This study identified that emotional safety was necessary for a child to reveal their needs and feelings, to explore new environments and experiences, and for a child’s social confidence to develop. Crucially, secure human relationships were the primary mechanism that facilitated this, highlighting a primary consideration for interventions aiming to engage children and youth with disabilities in physical activity pursuits.

In regards to our second aim, this study demonstrated a clear and consistent relationship between context, mechanisms and outcomes of the LEM intervention to generate a refined program theory. The theory described in Chapter Five illustrates that it is not a matter of a singular mechanism (or even a combination of mechanisms) asserting influence on one outcome, but the interaction of mechanisms and context as a whole that facilitates outcomes. As these findings were independent of age, gender, and disability of children, the testing and utilisation of this theory may be applied across a range of clinical settings. Importantly, this study addresses key recommendations arising from the Scoping Review in Chapter Two; identifying the relationships between components of programs to understand their influence on each other, and the roles of these relationships in creating positive participatory experiences.

8.1.6 Chapter Six, Paper Five


Chapter Six encompasses the last paper in the series arising from the evaluation of the LEM intervention. In understanding program mechanisms from the perspectives and behaviours of those receiving the intervention, Chapter Five was focussed on the outcomes of the child. In order to understand this from a truly family centred perspective, Chapter Six aimed to describe the experience of parents participating in the LEM intervention. Using grounded theory, this study became progressively focused as parents described a journey of becoming facilitators of a child’s participation in physical activity.
Forty four parents of children with disabilities participated in the study. The thematic concepts uncovered in this study constructed a theory describing the social process of learning and empowerment of the parents participating in the LEM. The theory encompasses three primary components; (i) active ingredients of the LEM intervention that enable learning and empowerment to transpire, (ii) learning and empowerment, referring to the social process through which parents gained knowledge, understanding and control over their role as facilitators of their child’s participation in physical activity, and (iii) outcomes of the process, including how practices acquired from the intervention continued as a part of family lifestyles in their local communities.

This study describes novel findings as to how parents can be empowered to embody facilitative roles, addressing a key recommendation from Chapter Three. The family-centred nature of the intervention was pivotal to this process. The opportunity for parents to participate in a range of physical activities with the appropriate supports (specialised staff, adaptive equipment and personalised instruction), enabled families to learn how to participate together, and discover possibilities that were not previously considered or believed to be achievable. Further, parents became aware of the benefits of physical activity, which prompted reflections on its importance amongst other priorities and across the lifespan. Parents’ active involvement in the intervention alleviated concerns and fears associated with their child, the activity, and the environment, addressing key family-related barriers outlined in the literature.

Parent learning and empowerment was not only a result of a parents needs being met, but also from highlighting existing abilities of parents and their child, and the resources already available in a families’ local environment. The group-based design created a social and support network for parents, enabling them to learn from and empower each other. Following the intervention, ongoing participation in physical activity continued as a shared enterprise of the parent group, and the support from others in similar situations that empowered parents to advocate for the full inclusion of their child in their community. A family-centred approach, including developing family-to family support and networking, is required to enhance physical activity participation outcomes for children and youth with disabilities. This is a central recommendation in Chapter Eight.
8.1.7 Chapter Seven, Paper Six

Involving Consumers and the Community in Paediatric Disability Research: Impacts, Outcomes, Processes, and Context.

Involving consumers and the community in the research process has been identified as a key knowledge translation strategy. Chapter Seven aimed to describe the impact and outcomes of consumer involvement throughout the studies in this thesis. Additionally, this Chapter aimed to examine the process(es) and context(s) of consumer involvement in the research project that fostered the impact and outcomes. A steering group (including an adolescent with a disability, two parents of children with disabilities, a paediatrician in rehabilitation medicine, two allied health professionals, a policy maker, and two representatives from community based disability services) was involved in all of the studies within this thesis, at various stages of the research process. The steering group attended five meetings over 24 months, and advised the research team on one scoping review and five original studies. A descriptive case study approach using scrutiny of relevant documentation was used to understand the context, processes and any impact of consumer involvement in the six papers.

In response to the first aim, the outcomes of this study demonstrate the broad impact of involving consumers and the community in research. The involvement of stakeholders occurred most frequently in method development and data analysis stages, and this was subsequently where the greatest impact was observed. Consumer involvement in the development of data collection tools identified lines of inquiry not previously considered and enhanced the user-relevance of the instruments. Similarly, involving stakeholders in the analysis process broadened the interpretation of data, and identified the aspects of research that had the most relevance to consumers. This evaluation demonstrates the positive impact of consumer involvement, both in terms of the research process and the overall project outcomes.

Addressing the second aim, this study identified key procedures and conditions that enabled consumer involvement to have an impact. Organisational, operational and dissemination processes were imperative to the likelihood of consumer involvement having an impact on the research. Specifically, researcher training was critical to ensuring the effectiveness of this engagement for consumers, the research and the community. A context that was values-based, membership-centred, and activity-based promoted stakeholder engagement, and successive impact and outcomes. Ultimately, this study demonstrates that consumer involvement can enhance the quality of childhood disability research,
ensure the relevance of results to the target group, and lead to accelerated dissemination and knowledge translation of research findings.

8.2 Conclusions

This research aimed to contribute to the evolving evidence surrounding physical activity participation, to improve the design and effectiveness of interventions in optimising these outcomes for children and youth with disabilities. Recommendations of the MRC complex interventions framework were applied to evaluate an existing intervention, and identify how and why the intervention works. Recommendations of the CIHR Knowledge-To-Action Cycle were also applied to this process, to identify and tailor knowledge needs, and adapt identified knowledge to a local context, to facilitate the knowledge translation process. How this thesis has addressed the recommendations from the MRC complex interventions framework and CIHR Knowledge-To-Action Cycle (initially described in chapter 1) is outlined in Table 8.1.
<table>
<thead>
<tr>
<th>CIHR Knowledge-To-Action Cycle recommendations 15</th>
<th>MRC complex interventions framework recommendations 14</th>
<th>How these are addressed in thesis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Action cycle</strong></td>
<td></td>
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</table>
| Identify the problem and the knowledge-action gaps: Identifying the knowledge-to-action gaps (knowledge needs) is the starting point of knowledge implementation and should involve relevant stakeholders. Needs assessments occur from the perspective of the target population and/or organisations. | Developing a complex intervention: It is important to begin thinking about implementation at an early stage in developing an intervention. | Chapter Seven, Paper Six:  
• Incorporation of a steering group at the beginning (and throughout) the research cycle, to ensure the relevance of the research to the needs of the target group (i.e. optimising participation outcomes for children with disabilities), and to foster knowledge translation to the wider community.  
• The steering group contributed to the needs assessment of families and organisations in the local Australian context, and to understanding how these needs are met for families at BHC.  
Appendix A:  
• Outcomes of the needs assessment of families with children with disabilities 22. |
| Knowledge inquiry and knowledge synthesis: The aggregation of existing ‘first generation knowledge’ (explored in knowledge inquiry); a summary that uses explicit methods to perform a comprehensive literature search and critical appraisal of studies. | Identifying the evidence base: Begin by identifying the relevant, existing evidence base, ideally by carrying out a systematic review. | Chapter Two, Paper One:  
• A scoping review method was identified as the most appropriate approach to investigate the initial research question, ‘What makes community programs work?’ Assessment of quality of the literature was included.  
• This review identified literature relating to meaningful experiences and optimal environments in community settings, and may assist professionals in the design of targeted interventions.  
• This review has been published 19. |
| Knowledge products: Consist of knowledge synopses which present knowledge in a clear, concise, and user-friendly format. These products provide explicit recommendations not only to | Evaluating a complex intervention: A key question in evaluating a complex intervention is whether the intervention works in everyday practice. If an experimental approach is not feasible, consider a good non-experimental alternative. | Chapter Three, Paper Two:  
• Given the nature of service delivery at BHC, a randomised evaluation design was not feasible. A pre-test post-test design was employed, as it resulted in no change to practitioners’ typical assessment schedule, nor additional disruption or burden to children and families accessing the service. This evaluation is representative of the model of service delivery in practice. |
meet stakeholders’ needs, but also to influence what stakeholders do - they facilitate the uptake and application of mature knowledge.

*Given the purpose of this research, we consider the publications of the primary studies a ‘knowledge product’. We believe these may influence and facilitate the design and evaluation of future interventions for both researchers and practitioners. Infographics, including plain language summaries, have also been developed for children, parents, and health professionals (Appendix B). The development of future knowledge products are described in the knowledge translation plan (Appendix B).

A crucial aspect of the design of an evaluation is the choice of outcome measures, and which outcomes are most important. Consider which sources of variation in outcomes are important, and carry out appropriate subgroup analyses.

<table>
<thead>
<tr>
<th>Evaluating a complex intervention:</th>
<th>Chapter Four, Paper Three:</th>
</tr>
</thead>
<tbody>
<tr>
<td>A second key question in evaluating complex interventions is how the intervention works, i.e. What are the active ingredients within the intervention?</td>
<td>Identified the active ingredients of the LEM intervention from the perspective of service delivery, and developed operational definitions to support future program implementation.</td>
</tr>
<tr>
<td>Identifying/developing appropriate theory: You should develop a theoretical understanding of the likely process of change, by drawing on existing evidence and theory, supplemented by new primary research, with those targeted by the intervention, or involved in its development or delivery. This should be done for intervention development, or as a part of the evaluation of an</td>
<td>These results are under review for publication.</td>
</tr>
</tbody>
</table>

Appendix B:
- A plain language summary in the form of an infographic has been developed for knowledge-users.

Chapter Five, Paper Four:
- Realist evaluation was employed to understand the likely process of change for children and youth participating in the LEM intervention.
- This was based on the perspectives of children with disabilities and their families targeted by the LEM intervention.
- A refined program theory was developed, describing the relationship between context, mechanisms and outcome(s) of the intervention.
- These results are under review for publication, to encourage further testing and utilisation of this theory in interventions and services.
intervention that has already been developed and/or implemented.

Appendix B:
- A plain language summary in the form of an infographic has been developed for knowledge-users.

Chapter Six, Paper Five:
- Grounded theory was employed to understand the experience of primary caregivers throughout the LEM intervention.
- This was based on the perspectives parents targeted by the LEM intervention.
- A theory of parent learning and empowerment was developed, describing the process of change for parents.
- These results are under review for publication, to encourage further testing and utilisation of this theory in interventions and services.

Appendix B:
- A plain language summary in the form of an infographic has been developed for knowledge-users.

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| Action cycle | Adapt knowledge to local contexts: Although knowledge products provide evidence in a usable form for practitioners and health settings, an important and additional necessary step is the adaptation of this knowledge to the context of use. | Implementation and beyond: Involve stakeholders in the choice of question and design of the research to ensure relevance. Use a multifaceted approach involving a mixture of interactive meetings, feedback, and local consensus processes. Make recommendations as specific as possible. | Chapter 7, Paper Six:
- Following five meetings held over 24 months, the steering group contributed to, and advised our research team, on one scoping review and five original studies. Meetings were interactive and activity-based.
- Stakeholders in the steering group were involved throughout the whole project, and across varying stages of the research cycle.
- Consumer involvement in the design stages of studies identified lines of inquiry not previously considered and enhanced the relevance of data collection instruments to the target population.
- Involving stakeholders in the analysis process broadened the interpretation of data, identified the aspects of research that had the most relevance to consumers, and adapted knowledge to local contexts.

Chapter 8, section 8.2.1 and 8.2.2:
- Based on the findings from this research, recommendations have been made for future research and clinical practice, including those related to the further stages within the Knowledge-to-Action Cycle. |
As Table 8.1 illustrates, this thesis comprehensively addresses key steps to bridge the knowledge-to-action gap to enable children and youth with disabilities to participate in physical activity. All steps outlined in the Knowledge Funnel of the Knowledge-To-Action Cycle are addressed, as are the beginning stages of the Action Cycle. Key recommendations of the MRC complex interventions framework that are not currently addressed (or addressed in the required detail) in related literature (including identifying and developing relevant theory, understanding change processes, and including implementation strategies) formed a primary focus of this thesis. The use of both frameworks and their complementary nature may encourage others to employ a similar approach in future intervention research.

It is important to note that this thesis was not able to address all stages of the Action Cycle. Prior to implementation, assessing the barriers of service providers, further tailoring of the intervention to local contexts, and the evaluation and monitoring of its outcomes, are all required steps that need to occur. As indicated on our knowledge translation plan (Appendix B), identified knowledge users also included researchers, as it was anticipated that further research would likely be required. We acknowledge the need to assess barriers to knowledge use by our target knowledge users, and evaluate and monitor the outcomes of our knowledge translation strategies. While this is not included in this thesis, this will form a component of the ongoing processes of this research.

Based on the interrelated findings of the papers in this thesis, the following conclusions are made that address the overall aim of this thesis, which may be applied by researchers and health professionals in the design of future interventions to optimise participation outcomes for children and youth with disabilities. Conclusions and recommendations were tailored in collaboration with the steering group.

8.2.1 SUPPORT AND RELATIONSHIPS ARE A PRIMARY MECHANISM THAT ENABLE INTERVENTIONS TO ELICIT OUTCOMES

Following investigation of the needs of families with children with disabilities in our local environment (Appendix A), the most significant facilitators to enabling participation were the presence of support and relationships, and the absence of support and relationships was identified as a primary barrier. A core component of this thesis was devoted to understanding how the LEM intervention addresses the needs of children with disabilities and their families in Norway. The main finding across all papers in this thesis was that support and relationships (for children, families, health professionals, and communities) are primary ingredients/mechanisms that enabled the intervention to work (i.e. produce meaningful outcomes for children and their families), and for practices acquired in the intervention to be sustained in local community settings. How these were operationalised for
multiple stakeholders involved in interventions, and how these approaches can be implemented to foster the longevity of outcomes attained from interventions, is detailed below.

FAMILY-CENTRED AND FAMILY-FAMILY-SUPPORT

Chapter Three determined that performance and satisfaction of physical activity participation goals were significantly higher at the end of the goal-directed, family-centred intervention, and at 12 weeks follow up, when compared to baseline. Chapter Four, Five, and Six identified the family-centred approach of the LEM as fundamental to enabling participation in physical activity and co-occurring meaningful outcomes for children and youth with disabilities. Family-centred principles were operationalised in the LEM by engaging the family in parts of the intervention (recognising they are the primary source of support to the child), providing an individualised, goal-directed service (acknowledging the uniqueness and diversity of children and families), staff embodying a strength-based perspective (family-centred care is competency enhancing rather than weakness focused), and embodying cooperation and mutual engagement with families in local communities (acknowledging that parents bring expertise to both the service and systems level, and the development of true collaborative relationships between families and health-care providers).

A key principle of family-centred practice is facilitating family-to-family support and networking, and delivering services that provide support to meet the needs of families. As described in Chapter Six, this was central to the learning and empowering experience of parents during the intervention, and their ability to facilitate and advocate for a child’s participation in physical activity in community settings. Ultimately, this fostered the development of facilitative attributes outlined in the literature that enhance a child’s physical activity participation. A family-centred approach, including family-to-family support and networking, is necessary to optimise physical activity participation outcomes for children and youth with disabilities.

CHILDREN AND YOUTH NEED TO FEEL SAFE: CONSIDER CONTEXT, AND THE HUMAN ENVIRONMENT.

If physical activity participation is the goal of the child and family, findings from Chapter Three encouraged health professionals to look beyond physiological and functional outcomes related to exercise, and focus on environmental, social and psychological attributes that may facilitate this. In Chapter Five, children revealed that they were able to participate, take on challenges, and develop social confidence, because the human environment created a context where they felt safe to do this. Children and youth explained that secure relationships were the primary mechanism that constructed this context, evolving from family-based, to staff and peer relationships. Parents described that time
was also a mechanism that facilitated the evolution of this ‘safe’ context, as this was integral to the development of friendships.

In attempts to engage children and youth with disabilities in physical activity pursuits, such mechanisms and contexts should be a primary consideration for intervention design, particularly as family and peer relationships assist in ongoing participation in physical activity after the intervention has ceased. In Chapter Two, a group-based intervention approach was suggested to foster the development of social networks similar to those embodied in community-based programs to encourage ongoing participation post-intervention. Camp-style, and/or group-based interventions, involving family and other children and youth with disabilities, may be feasible approaches that construct emotionally safe contexts.

CONNECT LOCAL COMMUNITIES

In order to ensure long-term changes in participation outcomes following targeted interventions, the availability and accessibility of services in local communities is paramount. This is a need identified by the steering group, and formed part of the main conclusions from Chapter Two and Three. To address this barrier, outcomes from Chapter Four and Six inferred that connecting communities may be an effective approach. There is large-scale cooperation between BHC and community-based health services, leisure and sporting associations, and universities, for resource capacity building in partnership with services in local communities. From the perspective of service provision, connecting with other service providers, having access to information and training, and having opportunities to share knowledge and experiences, created support networks that promoted this. The engagement of students completing tertiary qualifications across varying fields of allied health, was also identified as crucial for the translation of knowledge to local communities.

For parents and children, Chapter Four and Six described the central role of intervention groups coming from the same geographical region. This united families who had similar experiences, developed an ongoing support network for parents, and enabled them to adopt roles as knowledge brokers within their communities. This also enabled parents to recognise that without the support from health professionals, services and systems in their home communities, barriers surrounding accessibility and accommodation may still be present. In connecting communities to optimise participation outcomes for children and families, Chapters Two, Four and Six made the following suggestions; (i) application of the concept of ‘Communities of Practice’ within intervention designs, and (ii) consideration of ‘relationship-centred care’ 25,26, a network of relationships not only between
children, families and professionals, but also considering peers, mentors, and services in the community.

**GOOD STAFF MATTER**

Outcomes from Chapter Four and Five emphasise that behaviours and characteristics of health professionals are mechanisms for intervention effectiveness 27. According to staff in Chapter Four, support networks, transformational leadership 28 and strengths-based attitudes of health professionals were fundamental ingredients that drove service delivery practices. Multidisciplinary allied health teams, including physical activity specialists and students, with a comprehensive understanding of the environment were considered essential.

From the perspective of children and parents in Chapter Five, having access to specialised health professionals that provided an individualised service and were highly competent in facilitating physical activity participation was described as crucial to the outcomes of the program, and beyond. This is reinforced in Chapter Six, with parents describing a high level of satisfaction in regards to the ‘package’ of service delivery. Ultimately, skilled professionals play a compelling role in creating a positive environment and enabling a child’s participation during an intervention.

**8.2.2 A PARTICIPATION-FOCUSED APPROACH**

This thesis describes participation as both the focus and the outcome of intervention, which in itself promoted a range of additional outcomes. Participation as a focus, and its value to participants, was emphasised extensively throughout Chapters Two, Three, Four, Five and Six of this thesis, and was further reinforced by stakeholders guiding this research. In Chapter Two, the opportunity to participate contributed significantly to the overall meaning of the experience for the child and their family, and was also emphasised by collaborating stakeholders during their interpretation of data. This was a key ingredient identified in Chapter Six, whereby the opportunity to participate in a range of physical activities with the appropriate supports enabled families to find enjoyment in physical activity, and learn activities that the family could do and continue with together. Chapter Five described that participation in novel activities was a large contributor to a child’s engagement in the program over time, and was perceived to elicit outcomes at a body functions and activity level. In Chapter Four, participation in unstructured activities facilitated the development of friendships for children and youth. Given the identified importance and meaning this evokes for children and their families, and the range of outcomes it may promote, participation-focused designs should be a primary consideration for future interventions.
**8.2.3 Invest in the Future**

This thesis emphasises that we need consider the future of the child, and therefore also the future of the research, right from research inception. Participation in physical activity is necessary for optimal physical, emotional, and psychosocial outcomes of children, youth, and adults, with and without disabilities. Although the focus of this thesis was children and youth with disabilities, they too will grow and become adults. As parents recognised in Chapter Six, a child’s participation preferences and needs change over time, and access to support across the lifespan is required. This is recognised and accounted for by BHC, as identified in Chapter Three and Chapter Six. The LEM intervention entails children and families to return to BHC to receive support and guidance as their preferences change, and specific programs for young adults and adults facilitates individuals’ ongoing participation as they transition into new life stages. In other contexts, revolutions at a service, systems and policy level may be required to enable parents’ access to the support they require to facilitate their child’s physical activity participation, and for children to do this independently in the future.

Investing in the future of children and youth with disabilities means researchers also play a role. As suggested by the CIHR Knowledge-To-Action Cycle and MRC complex interventions framework, knowledge translation and implementation should be considered at the beginning of intervention development processes. A knowledge translation plan (Appendix B) was constructed in the planning stages of this research, and Chapter Seven described the involvement of consumers and the community throughout all of the research undertaken in this thesis. One of the most significant outcomes from consumer involvement was the accelerated dissemination and translation of knowledge. Stakeholders involved in our research adopted the role of knowledge brokers, promoting the integration of the best available evidence to tailor programs specific to the needs of the community. Involving consumers not only ensures research remains reflective of the needs of the community, but can also empower the community to respond to these needs.

**8.2.4 Future Research**

Based on the findings from this research, the following recommendations are made for future research in this field:

- The findings documented in Chapter Three, Four, Five and Six are from one rehabilitation centre in one country. Future research that evaluates the effectiveness and processes of interventions across other contexts addressing participation outcomes is desirable.
• All research included in this thesis was conducted in high income countries, including all research articles incorporated in the scoping review in Chapter Two. It is imperative that the needs of children and youth from other global localities and cultural backgrounds are determined, if we are to intervene effectively. Research methods such as participatory action research and measurement approaches such as yarning are culturally safe processes that may be useful in obtaining these perspectives. Given the global applicability of the ICF-CY and its utility throughout this thesis, future research may also consider the application of these findings in low and middle income countries by adapting this knowledge to local contexts.

• The findings from Chapter Three suggest that measuring multiple dimensions of participation is necessary to accurately document changes in physical activity participation in future interventions.

• While Chapter Four explored the experiences of service providers involved in the LEM, the needs of service providers in local settings should be considered prior to intervention development in other environments. Identifying barriers and facilitators to service provision, and understanding the receptivity and preparedness of services in the community, is a key knowledge translation strategy and will assist in enabling participation for children and youth with disabilities in community settings.

• Chapter Five demonstrated that interventions aimed at improving participation have the potential to influence other components of the ICF-CY. Parents’ perceptions of the participation-based intervention eliciting outcomes at the level of body functions and activity warrants further investigation. Future research may consider measuring outcomes at this level to determine if participation interventions are a feasible approach to improve impairments and activity limitations.

• In Chapter Five and Six, theoretical models were proposed that may optimise outcomes for child and parents, respectively. Future research should test these theories in practice, to determine their efficacy in optimising participation in physical activity for children and youth with disabilities across settings.

• Future research in family-centred participation interventions should attempt to target and measure parent empowerment and its relationship to child, parent and service-related outcomes of interest.

• The interrelated results discussed in Chapter Eight in this thesis should guide the design of future interventions, and be evaluated using randomised control trials. Knowledge translation and implementation should be considered at the beginning of intervention development processes.
• Consumers and the community should be involved in future research attempting to design, evaluate and implement interventions. Chapter Seven describes processes and contexts that facilitate this in childhood disability research.

8.2.5 Clinical Implications

Based on the findings from this research, the following recommendations for clinical practice are made:

• Interventions attempting to optimise physical activity should be goal-directed and family-centred. Goal setting should be collaborative between families and professionals, and directed by the child, to ensure the needs of all stakeholders are considered. Parents and siblings should be encouraged to participate in some (not all) of the activity components of the intervention to enable parent learning and ongoing facilitation of the child’s participation in physical activity.

• Endeavour to employ group-based designs assembled from the same regional area, to unite families and foster their development as knowledge brokers for communities, and facilitate peer learning and (continued) social networks for children and youth.

• Include support networks for health professionals and leisure-based service providers within intervention design. This may focus on enhancing practitioner and provider knowledge through training, regular meetings, enabling access to multidisciplinary teams and physical activity specialists, and/or creating opportunities to share professional experiences. Establishing inter-professional communication networks and creating equal partnerships with and between researchers, health-care practitioners, and leisure services in communities will enhance the translation and sustainability of physical activity participation across life settings of children and youth.

• Consider the environment from the outset of interventions. Confirm the accessibility and availability of services, equipment, and the built and natural environment relevant to the child’s physical activity goals and ongoing participation. Characteristics of the human environment, including strong leadership and strengths-based attitudes of health professionals and community service providers, and support and relationships for children and parents, are key ingredients of effective participation interventions.
8.2.6 Significance

Article 23 of the UN Convention on the Rights of the Child\textsuperscript{32} and Articles 23-30 of the 2006 UN Convention on the Rights of Persons with Disabilities\textsuperscript{33} state that children with disabilities should have the opportunity to participate on an equal basis with others in all life settings, and have access to services to promote participation. Despite this, it is well documented that children with disabilities experience significant participation restrictions, particularly in physical activity\textsuperscript{10}. This research addresses empirical evidence\textsuperscript{10,34} and consumer priorities\textsuperscript{35} that advocate the need to develop interventions that enhance participation outcomes. This thesis challenges the view that participation should be seen primarily as a flow on effect of rehabilitation, and instead promotes participation as a catalyst to foster meaningful outcomes across all levels of the ICF-CY. This thesis adds new knowledge regarding the optimisation of participation in physical activity through goal-directed and family-centred interventions for children with disabilities, and addresses key stages of intervention development and evaluation that have received little attention in the literature. Specifically, this research has (i), provided a synthesis of literature that describes the participation experience in community programs, identifying elements that may need to be considered for the continuation of practices following interventions; (ii), detailed active ingredients and associated operational definitions of an intervention from the perspective of service delivery, to promote future program implementation; (iii), provided an understanding of how an effective intervention works and the context that promotes meaningful outcomes, from the perspective of children and parents; (iv) constructed a theory detailing how parents of children with disabilities can be supported to become facilitators of physical activity participation; and (v), incorporated knowledge translation and implementation processes from the outset of the research, including consumer engagement. Together, this thesis may meaningfully address the needs of children and their families, facilitate the translation of effective interventions into practice, and enable children and youth with disabilities to participate in physical activity.
8.3 References


Appendices

APPENDIX A: ADDITIONAL PUBLICATIONS

Appendix A1

Can, Want and Try: Parents’ Viewpoints Regarding the Participation of Their Child with an Acquired Brain Injury

The PhD candidate, Claire E Willis, was an academic supervisor of the first author of this paper. The PhD Candidate was involved in the study design, data collection, data analysis, interpretation, and write-up of this published manuscript.
Can, Want and Try: Parents’ Viewpoints Regarding the Participation of Their Child with an Acquired Brain Injury

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Abstract

Background
Acquired brain injury (ABI) is a leading cause of permanent disability, currently affecting 20,000 Australian children. Community participation is essential for childhood development and enjoyment, yet children with ABI can often experience barriers to participation. The factors which act as barriers and facilitators to community participation for children with an ABI are not well understood.

Aim
To identify the viewpoints of parents of children with an ABI, regarding the barriers and facilitators most pertinent to community participation for their child.

Methods
Using Q-method, 41 parents of children with moderate/severe ABI sorted 37 statements regarding barriers and facilitators to community participation. Factor analysis identified three viewpoints.

Results
This study identified three distinct viewpoints, with the perceived ability to participate decreasing with a stepwise trend from parents who felt their child and family “can” participate in viewpoint one, to “want” in viewpoint two and “try” in viewpoint three.

Conclusions
Findings indicated good participation outcomes for most children and families, however some families who were motivated to participate experienced significant barriers. The most significant facilitators included child motivation, supportive relationships from immediate
family and friends, and supportive community attitudes. The lack of supportive relationships and attitudes was perceived as a fundamental barrier to community participation.

Significance
This research begins to address the paucity of information regarding those factors that impact upon the participation of children with an ABI in Australia. Findings have implications for therapists, service providers and community organisations.

Introduction
Acquired brain injury (ABI) is a leading cause of permanent disability among children worldwide [1, 2]. In Australia, approximately 20,000 children under the age of 15 years are currently living with an ABI, a figure which is increasing annually [3, 4]. Each ABI is unique and is influenced by the child’s developmental stage at the time of injury and the severity of the cause [2, 4]. Recovery from ABI is unpredictable, depending on the severity, children may regain their pre-injury skills or experience long-term physical, cognitive or behavioural impairments [6, 7]. Children with moderate to severe ABI (diagnosed according to immediate medical outcomes following injury) are likely to have difficulty with independence in everyday tasks [1, 5, 9]. These persisting issues can significantly impact their participation in everyday life [3, 8].

Participation is vital for development during childhood [10]. Participation in the community (typically leisure and recreation) provides children with the opportunity to explore their own personal interests, grow as individuals and most importantly, to enjoy life [11–13]. Understanding outcome-related participation is especially important when considering the impact of complex diagnoses like ABI, as they focus on the children’s involvement in life situations rather than on their impairments [5, 14]. However, children with moderate to severe ABI experience significant participation restrictions when engaging in social and community-based leisure activities [6, 15]. As a result, children with an ABI in Australia participate in more activities in the home environment with family members than with friends in the broader community [6].

Literature examining the barriers and facilitators to participation in children with ABI is limited [16]. However, due to the similarities in participation restrictions faced by children with ABI and children with neurodevelopmental disabilities, it is likely that they face similar barriers and facilitators. The International Classification of Functioning: Children and Youth Version (ICF-CY) provides a holistic framework to conceptualise the consequences of childhood ABI on participation [14]. The ICF-CY captures the dynamic interaction between health conditions (impairments), a child’s activity (carrying out an action or completing a task) and participation (involvement in life situations) in their ‘context’, inclusive of environmental and personal factors [14].

Within the ICF-CY, facilitators support a child’s participation, while barriers may cause participation restrictions [16]. For example, within the immediate family, parents can act as primary facilitators to their child’s participation by actively searching for opportunities, making their time available, and committing to providing individualised support [6, 17, 18]. Conversely, parents may inadvertently act as barriers to participation as they struggle to prioritise their competing demands of home, work, family and their own health [17]. Similarly, while friendships can motivate a child with a disability to participate in physical activity, sports and general play [17], a lack of friendships or difficulty making friends due to communication...
impairments, may act as a barrier to community participation. Other family-dependent environmental factors, such as physical geography and socio-economic status have been identified as possible barriers or facilitators to participation for children with disability [18, 29].

Societal attitudes have been identified as a significant barrier to participation in physical activities for children with a disability [12]. Furthermore, the invisible nature of ABI can lead to a lack of understanding from peers and professionals, contributing to participation restrictions [6]. While most services, systems and policies aim to be inclusive, there is a lack of services that truly facilitate community participation for children with disability [17]. This problem is often compounded by mainstream programs that are unwilling or unable to be inclusive [12]. Strong facilitators can include peers and community activity organiser who are accepting of children with ABI, and when families embrace the value of community participation embedded in many cultures, including Australian [19, 20].

The participation outcomes for children following an ABI are not well understood [6, 21-23]. While the aforementioned studies identify barriers and facilitators to participation for children with neurodevelopmental disabilities, there is still a need to determine their relative pertinence to ABI alone. Therefore, the aim of this study was to identify viewpoints of parents regarding what barriers and facilitators are most pertinent to the community participation of their child with an ABI.

Materials and Methods
The Q method was used to identify the viewpoints of the participants [24]. The Q method allows for exploration of experiences by asking each individual to conduct a Q-sort, sorting a set of predetermined statements onto a normally distributed grid (Fig 1) ranked from strongly agree, to strongly disagree. The completed Q-sort provides an overview of the participants’ viewpoints on the topic in question [24-36]. The fact that the grid comprises only as many possible positions as there are statements allows for a discrimination of viewpoints that may not be identifiable by simply identifying items in a questionnaire or through interviews [25, 22]. The Q-method employs both inductive and deductive approaches which enables an in-depth understanding of an array of participants perspectives and beliefs with regards to a particular topic of interest [24, 27, 28]. A Q-method does not require large numbers of participants as its goal is to identify the preferred viewpoints of a defined group, with between 40-60 participants considered sufficient to meet this aim [27, 29]. The Q-method involves five steps as described below: 1) developing the Q-concourse; 2) identification of statements; 3) administration of the Q-sort; 4) data analysis and 5) interpretation of factors in the context of the current study [25, 22, 30].

1. The Q-concourse for the current study was developed through a systematic review focused on identifying barriers and facilitators impacting on participation of Australian children with neurological impairments and a systematic review identifying elements that contribute to meaningful participation for children and youth with disabilities [24, 31].

2. Based on the concourse, 50 statements were identified and reviewed by an advisory steering group [22], developed to guide and direct a larger project that this study was designed to inform. The group included an adolescent with an ABI, parents of children and adolescents with an ABI, clinicians working in hospital and community settings, a disability policy advisor, and representatives from non-government organizations and community support centre. Following feedback from this group, the 50 statements were reduced to 37 statements (Table 1) and many wording changes were made. Overall, 62% of the original statements were changed on advice from the steering group. A speech pathologist reviewed the
statements for language errors and the final set of statements was piloted with three clien-
tisans from the ABI team at a children's hospital; a clinical psychologist, a clinical nurse spe-
dalist and an occupational therapist.

3. The Q-sort was distributed to 41 participants recruited through convenience sampling
whilst waiting to attend their child's routine ABI clinic appointment at a paediatric hospital
in Western Australia. Inclusion criteria were: parents of children aged 5–17 with an ABI at
least three months post-injury, and an ABI diagnosed as moderate/severe by a paediatrician.
Participants were given verbal instructions from a script to ensure consistency and inter-
nater reliability of the researchers. After written consent, the participants were asked to sort
the statements onto the 'grid' (see Fig. 1) according to a eleven-point continuum ranging
from -5 'strongly agree' to 0 for the 'neutral' column, and 5 for 'strongly disagree' [24, 25],
in order of perceived relative priority [27]. The participants were reminded that there were
no right or wrong places in regards to sorting the statements and that the completed Q-sort
would provide a snapshot of the participants' experience of the barriers and facilitators to
their child's participation at that point in time [23]. Upon completion of the Q-sort, parents
were asked if they perceived any statements irrelevant or missing, and a satisfaction score
was obtained in relation to the extent to which the participant felt that their final sort
Table 1. Q-sort Statements, Factor arrays of viewpoints (Ranking) and Z-scores, All Statements are Shown and Ordered According to Factor Loadings.

<table>
<thead>
<tr>
<th>Statements</th>
<th>Factor array (Z score)</th>
<th>Consensus or Contended statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. My child receives enough funding to cover their community activity needs</td>
<td>-1 (-0.57)</td>
<td></td>
</tr>
<tr>
<td>5. I feel obliged to supervise my child in their community activities</td>
<td>0 (-0.14)*</td>
<td></td>
</tr>
<tr>
<td>6. I have enough time to help my child participate in the community</td>
<td>2 (0.73)*</td>
<td></td>
</tr>
<tr>
<td>10. My child finds it difficult to play with other children</td>
<td>-5 (-1.96)*</td>
<td></td>
</tr>
<tr>
<td>12. My child is proud of participating in community activities that are meaningful to him/her</td>
<td>4 (1.22)</td>
<td></td>
</tr>
<tr>
<td>19. I feel discouraged when learning for community activities that are appropriate for my child</td>
<td>-3 (-1.22)*</td>
<td></td>
</tr>
<tr>
<td>24. There are enough activity programs that meet my child's needs</td>
<td>0 (-0.10)*</td>
<td></td>
</tr>
<tr>
<td>27. My child is easily able to participate in community activities</td>
<td>3 (1.15)*</td>
<td></td>
</tr>
<tr>
<td>32. Health professionals have helped encouraged my child to participate in the community</td>
<td>2 (0.77)*</td>
<td></td>
</tr>
<tr>
<td>33. My child finds it hard to participate in community because of their difficulty concentrating and/or paying attention</td>
<td>-2 (-1.67)</td>
<td></td>
</tr>
<tr>
<td>34. It is hard for my child to participate in community activities because of behavioural difficulties</td>
<td>-2 (-1.13)*</td>
<td></td>
</tr>
<tr>
<td>35. My stress levels influence how much I am able to help my child participate in community activities</td>
<td>0 (0.03)</td>
<td></td>
</tr>
<tr>
<td>14. I don't need to travel long way to get to community activities that are suitable for my child</td>
<td>0 (0.20)</td>
<td></td>
</tr>
<tr>
<td>18. My child wants to do whatever his/her friends and/or siblings do in the community</td>
<td>3 (0.98)</td>
<td></td>
</tr>
<tr>
<td>21. It is not difficult to get my child to and from community activities</td>
<td>1 (0.54)</td>
<td></td>
</tr>
<tr>
<td>37. My family has been motivated to participate in the community</td>
<td>1 (0.09)</td>
<td></td>
</tr>
<tr>
<td>9. Adults supervising activities in the community make an effort to include my child</td>
<td>2 (0.77)</td>
<td></td>
</tr>
<tr>
<td>13. Mainstream community activity programs include my child</td>
<td>0 (0.37)</td>
<td></td>
</tr>
<tr>
<td>29. My child has enough energy to complete community activities</td>
<td>3 (0.96)</td>
<td></td>
</tr>
<tr>
<td>30. My child finds it hard to participate in the community because of mobility difficulties</td>
<td>-2 (-1.49)</td>
<td></td>
</tr>
<tr>
<td>12. People in the community understand my child's ABI, they are welcoming and know how to interact with my child</td>
<td>1 (0.01)*</td>
<td></td>
</tr>
<tr>
<td>11. My child has friends in and out of school</td>
<td>5 (2.04)*</td>
<td></td>
</tr>
<tr>
<td>26. My child's school organizes out-of-school events that are inclusive</td>
<td>-1 (-0.60)</td>
<td></td>
</tr>
<tr>
<td>22. Community activities suitable for my child are within my family's budget</td>
<td>1 (0.04)</td>
<td></td>
</tr>
<tr>
<td>25. It makes me happy when my child enjoys participating in community activities</td>
<td>4 (1.90)</td>
<td></td>
</tr>
<tr>
<td>36. My child is motivated to participate in activities in the community</td>
<td>2 (0.86)</td>
<td></td>
</tr>
<tr>
<td>31. My child finds it hard to participate in the community because of communication difficulties</td>
<td>-4 (-1.30)</td>
<td></td>
</tr>
<tr>
<td>1. Actively seek opportunities for my child to participate in the community</td>
<td>1 (0.95)</td>
<td></td>
</tr>
<tr>
<td>16. My child does not enjoy learning new skills and is not persistent with learning new skills</td>
<td>-3 (-1.27)</td>
<td></td>
</tr>
</tbody>
</table>

(Continued)
represented their viewpoint [35, 34]. Data was collected on length of time to complete the Q-sort and the participant’s relationship to the child. Additionally, data was gathered to complete an Index of Relative Socio-economic Disadvantage [32], to classify the participants as residing in remote, outer regional or metropolitan areas [33].

4. Each participant’s pattern of statements (Q-sort arrangement) was manually entered into the PQ Method program [35], in which a per-person factor analysis was conducted, in order to identify the most prominent viewpoints. Five consecutively fulfilled criteria were used in order to select factors [36]. They consisted of: 1) the “magic number seven” which is the default minimum number of factor extraction in PQ Method, 2) the Kaiser-Guttman Criterion, which allows factors with an eigenvalue greater than 1.0 to be retained [37, 38], 3) Two significantly loading sorts’ states that at least two significant factor loadings are required per retained factor, 4) Humphrey’s rule, which states that when multiplied, the sum of the two significant factors with the highest (positive and/or negative) rankings must be greater than twice the standard error and 5) the ‘Scre test’, which indicates that factors displayed prior to the scree plot ‘levelling out’ should be retained (see Fig. 2) [39]. These five criteria justified the inclusion of three factors for further data analysis and interpretation.

![Fig 2. Scree Plot Demonstrating the Inclusion of Three Factors.](doi:10.1371/journal.pone.0157851.g002)
Various rotation was run on the three factors, determining the best solution for the explained variance, and the individual sorts which significantly (p < 0.05) loaded onto each factor were then uncovered [28]. This process ensured that participants did not load onto more than one factor, thus revealing the distinct viewpoints among the participants [36].

5. Interpretation of results. Data interpretation commenced with naming the three factors (which are henceforth synonymous with ‘viewpoints’). This was a collaborative process including four clinicians in the field of ABI and participation. Discussion regarding each viewpoint’s defining statements was held until consensus was reached and each viewpoint was named.

Ethical considerations

The procedures of this study conformed to the Declaration of Helsinki [29], and ethical approval was received from Curtin University, Perth, Western Australia (HR03/2014), The University of Western Australia Perth, Australia (RA/4/1/6556), and Princess Margaret Hospital (2013/099). Participants were provided with an information sheet explaining the aim of the project, how data was to be confidentially stored and de-identified in any presentation of results. Furthermore, participants were reminded that they could withdraw at any time without penalty. Informed verbal and written consent was obtained from parents prior to the administration of the Q-sort. The individual shown in Fig 1 of this manuscript has provided written informed consent (as outlined in PLOS consent form) to publish their image.

Results

A total of 41 parents participated in the Q-sort task and participant demographics regarding both parents and the children represented are presented in Table 2. The Q-sort took an average time of 1.5 minutes to complete. Two participants were excluded due to incomplete sorts. Three distinct viewpoints were defined by the remaining 39 participants. Six participants were mother and father dyads, representing three children with ABI. Of these three parental dyads recruited, only one pair had both parents aligned with the same viewpoint (viewpoint one), while one was split between viewpoint one and viewpoint two, and the others were split between viewpoints one and three. Distinguishing statements for each factor and the factor array or ‘typical sort’ of each statement for each factor are presented in Table 1. This table also presents seven consensus statements, and the seven most contended statements between viewpoints.

Table 3 presents the individual participant demographics, arranged according factor loadings, or degree of alignment with their represented viewpoint. Statements defining each viewpoint are discussed. The statement’s relative positioning on the typical Q-sort for that viewpoint, i.e. (+5 strongly agree to -5 strongly disagree) will be included in parentheses as follows (statement number, position).

Viewpoint one: “We can participate!”

Viewpoint one accounted for 26.8% of the variance, with 23 participants (56%) significantly associated with this factor. A total of 13 mothers and 10 fathers, (including one parental dyad), represented 22 children with ABI. Children were aged between 5 and 17 years old (with a mean of 11.3 years old) and were between 0.25–13.4 years post injury (a mean of 4.8 years post injury). This viewpoint included all three families from remote (Western) Australia, one family from other regional (Western) Australia and all three of the Indigenous Australian children. Ten (44%) of the families in viewpoint one resided in areas of socio-economic disadvantage, eight families (35%) resided in advantaged areas and the remaining five families lived in
Table 2. Participant Demographics.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents completing Q-sort</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers</td>
<td>13 (57%)</td>
<td>9 (100%)</td>
<td>4 (57%)</td>
</tr>
<tr>
<td>Fathers</td>
<td>10 (40%)</td>
<td>0</td>
<td>5 (40%)</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Children represented</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total*</td>
<td>22</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Age in years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>11.3</td>
<td>12.2</td>
<td>13.3</td>
</tr>
<tr>
<td>Median</td>
<td>12</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9 (39%)</td>
<td>3 (22%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Male</td>
<td>14 (66%)</td>
<td>6 (67%)</td>
<td>5 (71%)</td>
</tr>
<tr>
<td>Time since injury in years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>4.8</td>
<td>6.1</td>
<td>5.3</td>
</tr>
<tr>
<td>Range</td>
<td>0.25–13.4</td>
<td>1.1–15.4</td>
<td>0.25–13.7</td>
</tr>
<tr>
<td>Birthplace</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WA</td>
<td>14 (60%)</td>
<td>6 (67%)</td>
<td>1 (14%)</td>
</tr>
<tr>
<td>Australia—other</td>
<td>7 (30%)</td>
<td>1 (11%)</td>
<td>3 (40%)</td>
</tr>
<tr>
<td>International</td>
<td>1 (4%)</td>
<td>2 (22%)</td>
<td>3 (43%)</td>
</tr>
<tr>
<td>Indigenous Australian</td>
<td>2 (8%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Yes</td>
<td>2 (14%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No</td>
<td>19 (86%)</td>
<td>9 (100%)</td>
<td>7 (100%)</td>
</tr>
</tbody>
</table>

* Two children whose parents load onto separate factors have been represented in both factors.

doi:10.1371/journal.pone.0127361.t002

average areas. The typical sort (Fig 1) demonstrates the average Q-sort arrangement of a parent from viewpoint one.

Viewpoint one was characterised by positive perspectives from parents regarding their child’s community participation; we can participate. The children were readily able to participate in community activities (statement 27: +3 agree) and were proud of doing so (17: +4). These children did not find it difficult to play (10: -5) with their friends, both in and out of school (11: +5), whom also motivated them to participate (18: +3). These children were able to focus their attention (33: -2), communicate (31: -4), manage their frustration (8: -1) and behave appropriately (34: -2) in community activities. Furthermore, these parents, relative to the other viewpoints, did not feel obliged to supervise their child (5: 0). Parents with viewpoint one, more so than the parents of other viewpoints, felt that people in the community understood, and were inclusive towards their child with an ABI (12: +1) and that health professionals had facilitated community participation through encouragement (32: +2).

Parents in viewpoint one felt that they had enough time to facilitate community participation (6: +2), did not feel discouraged when searching for opportunities for their child (19: -3), and felt more positively than parents of other viewpoints about the availability of suitable activities (24: 0). Although these parents felt their child did not receive enough funding for community activities (4: -1), suitable activities were usually within their family’s budget (22: +1). Parents in viewpoint one felt that community participation was important (28: 0) and they strongly agreed that it made themselves feel happy when their child was engaged in community activities (25: +4).
Table 3. Individual participant demographics, arranged according to factor loading.

<table>
<thead>
<tr>
<th>Parental Status</th>
<th>Age of child with ABI</th>
<th>Child Gender</th>
<th>Indigenous Status</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>6</td>
<td>Male</td>
<td>no</td>
<td>0.789</td>
<td>-0.001</td>
<td>0.255</td>
</tr>
<tr>
<td>Father</td>
<td>7</td>
<td>Male</td>
<td>no</td>
<td>0.736</td>
<td>-0.275</td>
<td>0.131</td>
</tr>
<tr>
<td>Mother</td>
<td>12</td>
<td>Male</td>
<td>no</td>
<td>0.726</td>
<td>-0.094</td>
<td>-0.021</td>
</tr>
<tr>
<td>Father</td>
<td>12</td>
<td>Female</td>
<td>no</td>
<td>0.711</td>
<td>0.078</td>
<td>0.152</td>
</tr>
<tr>
<td>Father</td>
<td>16</td>
<td>Male</td>
<td>no</td>
<td>0.740</td>
<td>0.317</td>
<td>-0.114</td>
</tr>
<tr>
<td>Father</td>
<td>9</td>
<td>Male</td>
<td>no</td>
<td>0.596</td>
<td>-0.018</td>
<td>-0.003</td>
</tr>
<tr>
<td>Mother</td>
<td>15</td>
<td>Male</td>
<td>no</td>
<td>0.695</td>
<td>0.288</td>
<td>0.140</td>
</tr>
<tr>
<td>Father</td>
<td>7</td>
<td>Male</td>
<td>yes</td>
<td>0.640</td>
<td>-0.206</td>
<td>0.257</td>
</tr>
<tr>
<td>Father</td>
<td>9</td>
<td>Female</td>
<td>no</td>
<td>0.610</td>
<td>0.313</td>
<td>0.030</td>
</tr>
<tr>
<td>Mother</td>
<td>6</td>
<td>Female</td>
<td>no</td>
<td>0.666</td>
<td>0.204</td>
<td>0.003</td>
</tr>
<tr>
<td>Father</td>
<td>13</td>
<td>Male</td>
<td>yes</td>
<td>0.601</td>
<td>0.134</td>
<td>0.002</td>
</tr>
<tr>
<td>Father</td>
<td>13</td>
<td>Male</td>
<td>yes</td>
<td>0.514</td>
<td>0.346</td>
<td>-0.241</td>
</tr>
<tr>
<td>Father</td>
<td>15</td>
<td>Male</td>
<td>no</td>
<td>0.535</td>
<td>0.275</td>
<td>-0.046</td>
</tr>
<tr>
<td>Father</td>
<td>17</td>
<td>Male</td>
<td>no</td>
<td>0.526</td>
<td>0.396</td>
<td>0.219</td>
</tr>
<tr>
<td>Father</td>
<td>12</td>
<td>Male</td>
<td>no</td>
<td>0.824</td>
<td>0.299</td>
<td>0.135</td>
</tr>
<tr>
<td>Father</td>
<td>16</td>
<td>Female</td>
<td>no</td>
<td>0.495</td>
<td>-0.049</td>
<td>0.225</td>
</tr>
<tr>
<td>Mother</td>
<td>11</td>
<td>Male</td>
<td>no</td>
<td>0.484</td>
<td>0.125</td>
<td>0.134</td>
</tr>
<tr>
<td>Mother</td>
<td>10</td>
<td>Male</td>
<td>no</td>
<td>0.471</td>
<td>0.430</td>
<td>0.039</td>
</tr>
<tr>
<td>Mother</td>
<td>15</td>
<td>Female</td>
<td>no</td>
<td>0.387</td>
<td>-0.130</td>
<td>-0.462</td>
</tr>
<tr>
<td>Father</td>
<td>15</td>
<td>Female</td>
<td>no</td>
<td>0.221</td>
<td>-0.066</td>
<td>0.168</td>
</tr>
<tr>
<td>Father</td>
<td>13</td>
<td>Female</td>
<td>no</td>
<td>0.095</td>
<td>0.022</td>
<td>-0.365</td>
</tr>
<tr>
<td>Mother</td>
<td>8</td>
<td>Female</td>
<td>no</td>
<td>0.064</td>
<td>0.086</td>
<td>0.259</td>
</tr>
<tr>
<td>Mother</td>
<td>6</td>
<td>Female</td>
<td>no</td>
<td>0.158</td>
<td>0.565</td>
<td>0.016</td>
</tr>
<tr>
<td>Mother</td>
<td>17</td>
<td>Male</td>
<td>no</td>
<td>0.219</td>
<td>0.565</td>
<td>0.000</td>
</tr>
<tr>
<td>Mother</td>
<td>13</td>
<td>Male</td>
<td>no</td>
<td>0.065</td>
<td>0.563</td>
<td>0.015</td>
</tr>
<tr>
<td>Mother</td>
<td>11</td>
<td>Female</td>
<td>no</td>
<td>0.002</td>
<td>0.459</td>
<td>-0.155</td>
</tr>
<tr>
<td>Mother</td>
<td>10</td>
<td>Male</td>
<td>no</td>
<td>0.305</td>
<td>0.446</td>
<td>0.249</td>
</tr>
<tr>
<td>Mother</td>
<td>15</td>
<td>Male</td>
<td>no</td>
<td>0.312</td>
<td>0.832</td>
<td>0.154</td>
</tr>
<tr>
<td>Mother</td>
<td>15</td>
<td>Male</td>
<td>no</td>
<td>0.048</td>
<td>0.377</td>
<td>0.257</td>
</tr>
<tr>
<td>Father</td>
<td>15</td>
<td>Male</td>
<td>no</td>
<td>0.067</td>
<td>0.302</td>
<td>-0.070</td>
</tr>
<tr>
<td>Father</td>
<td>12</td>
<td>Male</td>
<td>no</td>
<td>0.228</td>
<td>0.157</td>
<td>0.921</td>
</tr>
<tr>
<td>Mother</td>
<td>14</td>
<td>Male</td>
<td>no</td>
<td>0.183</td>
<td>0.420</td>
<td>0.478</td>
</tr>
<tr>
<td>Father</td>
<td>17</td>
<td>Female</td>
<td>no</td>
<td>0.407</td>
<td>0.194</td>
<td>0.475</td>
</tr>
<tr>
<td>Mother</td>
<td>11</td>
<td>Female</td>
<td>no</td>
<td>0.323</td>
<td>0.359</td>
<td>0.463</td>
</tr>
<tr>
<td>Father</td>
<td>17</td>
<td>Male</td>
<td>no</td>
<td>0.020</td>
<td>0.117</td>
<td>0.414</td>
</tr>
<tr>
<td>Father</td>
<td>14</td>
<td>Male</td>
<td>no</td>
<td>0.270</td>
<td>0.255</td>
<td>0.389</td>
</tr>
<tr>
<td>Mother</td>
<td>8</td>
<td>Male</td>
<td>no</td>
<td>0.103</td>
<td>-0.032</td>
<td>0.201</td>
</tr>
</tbody>
</table>

**Notes:**
- Data from both mother and father collected, representing one child.
- Table column titles: Parental Status, Age of child with ABI, Child Gender, Indigenous Status, Factor 1, Factor 2, Factor 3.

Viewpoint two: “We want to participate”

Viewpoint two accounted for 10.5% of the variance, with nine participants (23%) significantly associated with this factor. These participants were all mothers who identified as non-Indigenous. Those nine parents represented children aged between 6 and 17 years old (with a
mean of 12.2 years old) and were between 1.1 and 13.4 years post injury (a mean of 6.1 years post injury). All of these families lived in major cities of Western Australia, with over half (56%) residing in areas of socio-economic disadvantage, two families (21%) residing in an area of socio-economic disadvantage and the remaining two (22%) living in socio-economically average areas.

The parents sharing viewpoint two felt very strongly that their children wanted to participate in community activities (we want to participate) (35; -5) and were proud of doing so (17; +4), even though they found participating somewhat difficult (27; -1). The children wanted to do what their friends of siblings did in the community (18; +4). However, they did not have friends both in and out of school (11; -1) and could find it more difficult to play with other children (10; -2) and experienced difficulties with communication (31; +1) and attention (33; +1).

Even though parents in viewpoint two strongly agreed that it made them happy when their child enjoyed participating (25; +5), family motivation to participate in the community was the lowest across all viewpoints (37; -1). These mothers indicated that their stress levels influenced how much they were able to facilitate their child’s community participation (3; +2), that they were not receiving enough funding (4; -4) and were experiencing financial constraints because of their family budget (22; -3). Compounding this, needing to travel long distances (14; -2) made getting their child to community activities difficult (21; -3). These mothers also felt that people in their communities were not always inclusive or understanding (12; -1) and that they had to educate supervising adults on how to include their child (2; +3).

**Fig 3. Typical Q Sort from Viewpoint One: We Can Participate.**

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Viewpoint three: "We try to participate…"

Viewpoint three accounted for 7.6% of the variance with the remaining seven participants (18%) significantly associated with this factor. These participants represented seven non-indigenous children, all residing in metropolitan areas. Children were aged between 8 and 17 years old (mean = 13.3 years old) and ranged from 0.25-13.7 years (mean = 5.3 years) post injury. Of the seven families, one family (14%) resided in an area of socio-economic disadvantage, two (29%) resided in an average economic areas, and four (57%) resided in advantaged areas.

Parents in viewpoint three felt that their children found participating in the community difficult (37; ±2), but were proud of participating in the community when they were able to (17; ±5); we try to participate. Children represented in viewpoint three did have friends in and out of school (11; ±2), and a role model that encouraged them to participate (7; ±2). However, these children, as opposed to those in the other viewpoints, had mobility difficulties (30; ±3), behavioral difficulties (34; ±1) including managing frustration (8; ±4), and experienced fatigue (29; ±1), adversely impacting upon their participation.

The parents felt happy when their child participated (29; ±4) but felt the most obligated of the three viewpoints to supervise their children (5; ±3). Parents in viewpoint three felt that their child’s school did not organise inclusive out of school events (28; ±4) and that community activities suitable for their children were not advertised widely enough (22; ±4), leaving parents feeling discouraged when searching for opportunities (19; ±2). Financially, suitable activities were not within the family’s budget (22; ±1), nor within the child’s funding (4; ±3). Parents in this viewpoint strongly felt that their child was not welcomed or included by people in their community (12; ±5), nor into mainstream activities (12; ±2).

Consensus and contested statements

Consensus and contested statements are presented in Table 1 and are discussed below in the following format; Statement number, Viewpoint one position, Viewpoint two position, Viewpoint three position. Parents from all viewpoints strongly agreed that it made them happy when their child enjoyed participating (25; V1: ±4, V2: ±5, V3: ±4) and agreed that they sought opportunities for their child to participate in the community (1; V1: ±1, V2: ±1, V3: ±1). Parents also agreed that their children with ABI were motivated to participate (36; V1: ±2, V2: ±3, V3: ±0), were proud of participating (17; V1: ±4, V2: ±4, V3: ±5), and enjoyed learning new skills (16; V1: ±3, V2: ±3, V3: ±2). Suitable community activities did not have long wait lists (26; V1: ±1, V2: ±1, V3: ±2), and parents agreed that feeling isolated when their child participated in the community was not an important facilitator (15; V1: ±0, V2: ±1, V3: ±0).

Contested statements (i.e. where the parents’ viewpoints differed the most) included whether or not children had friends both in and out of school (11; V1: ±5, V2: ±1, V3: ±2), found it difficult to play with other children (10; V1: ±5, V2: ±2, V3: ±3), or whether or not their mobility (30; V1: ±2, V2: ±2, V3: ±3) or communication skills (31; V1: ±4, V2: ±1, V3: ±3) hindered their ability to participate in the community. Whether or not it was difficult to get their children to and from community activities (21; V1: ±1, V2: ±3, V3: ±1) was also contested across the viewpoints. Parents in different viewpoints had different experiences with whether or not people in the community understood ABI and knew how to interact with and welcome their child (12; V1: ±1, V2: ±1, V3: ±5), and whether or not their child’s school organised inclusive out of school events (26; V1: ±1, V2: ±0, V3: ±4).

In this study content validity was addressed by asking the participants for feedback regarding the relevancy of the statements [34]. Of the parents who responded to this question, most (n = 11/18) reported that the statements were relevant to their child and family; three stated they wanted more agree or disagree spaces on the grid and four parents felt the Q-sort was not
relevant to their family. Face validity was assessed by asking parents how satisfied they were with their finalised sort on a scale of 1 'very unsatisfied' to 5 'very satisfied' [43]. The median satisfaction score reported was four, with a range from three to five. Only one suggestion for what could have been added to the Q-sort was made, which was to include continence issues.

Discussion

While each of the three viewpoints revealed that parents agreed upon some of the facilitators and barriers to their child’s community participation each presented a unique perspective on this topic. The most significant consensus was that participating in meaningful activities made their child proud, and parents agreed that their child was motivated to participate and enjoyed learning new skills. It is likely that the experience of success contributed to positive participation experiences [28, 31], motivated continued participation [44, 45], and pointed to the importance of psychological factors in facilitating participation outcomes. Parents themselves were instrumental facilitators of their child’s participation, seeking opportunities for their children to participate and strongly agreeing that they felt happy when their child enjoyed community participation. Parents are instrumental in selecting the right opportunities for their child, maximising the psychological benefits of participation experiences [23].

Viewpoint one, “We can participate”, included the majority of the participants and suggested that their parents felt their children had good participation outcomes post-ABI. Due to the paucity of research into ABI in Australia [43], this is an important and encouraging finding. This viewpoint emphasised the child’s ability to participate and the positive social support and attitudes that facilitated the family’s participation. Parents perceived their children as able, proud and motivated, with friends that facilitated their participation. Supportive relationships, including the child’s parents, health professionals, supervising adults and people in the community were all facilitators of these children’s participation.

This viewpoint aligns strongly with literature reporting that supportive relationships facilitate children’s participation [12]. The presence of friendships and ease of play was a significant facilitator for the most prominent viewpoint in this study and the absence of these friendships was a significant barrier. Research into the lived experience of children with disabilities regarding their inclusion has also reported this dilemma; that while friendships facilitate participation, they are not always present [33]. A recent literature review described similar facilitators including experiencing a sense of connectedness, belonging and having authentic friendships, family support and role models to be essential elements contributing to meaningful participation experiences for children and youth with disabilities [41]. This suggests that supportive relationships should be a primary consideration when aiming to facilitate the community participation of children with ABI.

Of note to therapists, parents of adolescents with Down syndrome have reported that the social feature of group therapy interventions was a major facilitator of their child’s participation [44]. Parents of children with disabilities have emphasised the importance of opportunities for families in similar situations to network and support each other [31]. Building networks with other families of children with a disability supports family resilience [45] and participating as a family unit contributes to better participation outcomes for the child with a disability [12]. Embedding community-based participation programs within a broader social framework such as a network of other programs or schools in which youth with disabilities and families are already connected contributes to better outcomes for children with disabilities [46]. These are all considerations for therapists and organisations aiming to facilitate better community participation for families of children with disabilities.
Viewpoint Two, "We want to participate..." demonstrated that families wanted to participate but were restricted by barriers at the environmental level. For these parents, participation was impeded by the parents' stress levels, financial constraints and distance from community activities. The emphasis of the pragmatic aspects of community participation expressed by families within this viewpoint highlights the need for interventions which focus on remediating some of these environmental barriers.

Australian parents have suggested that modifying tasks and the environment would improve their child's participation post ABI [43]. "Context therapy" is an intervention that focuses solely on environmental and task modifications, and does not attempt to remediate impairments or factors specific to the child [47]. This approach has demonstrated effectiveness in studies with children with Cerebral palsy [47-49]. A recent systematic review also concluded that context therapy is one of the most effective interventions for improving the participation outcomes of children with Cerebral palsy [49]. However, the appropriateness of this intervention in a participation setting with children with ABI is unknown. Given that many barriers to participation are environmental and contextual in nature for children with ABI, context therapy may prove to be particularly effective in enhancing participation outcomes.

Family-centred practice has long been recognized as effective in improving the participation outcomes of children with disabilities [50-52]. However, while a family-centred approach to practice has been encouraged by parents, they have also called upon service providers to consider including practical strategies to minimize environmental barriers, such as the cost of programming, inaccessible parking and organizing activities according to parental availability and geographical location [43]. While therapists are adept at grading and adapting activities and interventions to meet the specific needs of the children, working to empower and build parental capacity and address environmental barriers may also assist in improving participation outcomes for children with ABI.

As this viewpoint demonstrates, parents are key elements in the child's environment, and have a major role in facilitating community participation outcomes. Occupational performance coaching aims to empower parents with the skills to create enabling environments for not only their child with a disability but their whole family [52]. This stepwise, structured approach is similar to that of solution-focused therapy and strengthens parents' capability for problem-solving and engenders a positive vision for the future [52]. More research is needed to understand the applicability of this approach to families living with a child with ABI.

Across the three viewpoints parents' contested whether or not people in the community understood ABI, or whether they were welcoming and inclusive. The social model of disability, while recognizing the impact of impairment, identifies that constraints in the social environment are often one of the most significant barriers to participation [53, 54]. According to children with disabilities, positive interpersonal interactions are central to inclusion [55]. Simply having the opportunity to participate is important for children with disabilities [56]. Findings from the present study show that when communities are inclusive of children with an ABI, they facilitate their participation in their community; however, a lack of inclusive attitudes and actions are a clear barrier to community inclusion. Similarly, community program design has been found to be a major barrier to the inclusion of children with disabilities [57]. The community has an important role in social inclusion and future research should investigate public awareness of ABI and how this may affect their community participation [57, 56].

Viewpoint three, "We try to participate..." reflected that all aspects of the ICF-CY impacted upon their child's ability to engage in meaningful community participation. Parents noted that participation was difficult. Environmental barriers such as societal attitudes and a lack of supportive relationships were emphasised, including being marginalised in the community and excluded from mainstream activities. This viewpoint highlighted that community participation
is a multi-faceted experience, a finding also emphasised in other childhood participatory research [31]. These findings extend the ICP-CY definition of participation as involvement in a life situation, highlighting that 

**Optimal participation is a personal, subjective experience, through which children are able to derive meaning from their engagement in life** [21]. While the ICP-CY has proved to be a useful model for use by researchers and therapists alike, this research adds to the growing call for the ICP-CY to encompass the important subjective psychological aspects of participation [31, 58, 59]. As occupational therapists have long since understood the link between participation and health [60], there is a clear opportunity to translate this paradigm into models of service delivery. This also supports the need to develop subjective measures of participation to capture the qualitative nature of engagement and meaning for children with disabilities [31, 59].

**Limitations**

Due to the nature of data collection, no measure of impairment was administered, limiting the ability of the researchers to further analyse the relationship between the severity of ABI and the viewpoints discovered, beyond the moderate/severe ABl diagnosis. Participants were also purposefully recruited from a hospital clinic and may not have been representative of all parents of children with ABI. This study addressed trustworthiness through the use of a steering group and by having expert researchers review findings to ensure confirmability [61]. Credibility was addressed by the primary researcher using reflective techniques throughout the data collection and analysis process [62]. Transferability was addressed by participants being chosen purposefully (within a selection criteria), and description of demographic information and research context [63].

Although the pre-determined nature of Q methodology can be criticised [64], the statements were developed using a systematic review and were changed extensively following feedback from the steering group. The strength of Q-sort technique is its forces prioritisation of items to reveal viewpoints, a strength which was key in choosing this methodology [26]. While the small sample size was appropriate for discovering the finite set of viewpoints as in Q-sort methodology literature [35], a Q-sort study can never be completely exhaustive, but provides a distillation of available information [39]. Overall, this research demonstrated that Q-methodology is a robust research method that can be used in busy clinical environments.

**Conclusions**

This study demonstrates that community participation is a complex experience and service providers and community recreation organisations targeting this outcome must take into consideration environmental barriers. Three viewpoints were identified regarding barriers and facilitators to community participation in children with ABI. Viewpoint one: “We can participate!”, Viewpoint two: “We want to participate…” and Viewpoint three: “We try to participate…” These findings indicate good participation outcomes for most children and families; however, some families who were motivated to participate experienced significant barriers. The most significant facilitators included motivation and supportive relationships from immediate family, friends and community attitudes. The lack of supportive relationships and attitudes was perceived as a fundamental barrier to community participation.

Q-methodology proved effective in not only uncovering prominent viewpoints from parents but also in identifying significant barriers and facilitators impacting the community participation of children with ABI. The successful implementation of Q sorts in a busy clinical environment should encourage further use of this methodology by therapists and service providers.
Key Points

- The most prominent viewpoint of parents who have children with Acquired Brain Injury in Western Australia was that their family is able to participate in the community, due to supportive relationships and attitudes.
- Children having friends, feeling proud of participating and parents being pleased as a result are significant facilitators for participation.
- A lack of friends and unsupportive or exclusive community attitudes were barriers to community participation for children with an ABI.
- Future research should examine the effectiveness of interventions at the environmental level (family-centred practice, context therapy and occupational performance coaching) in removing barriers to community participation for children with ABI.

Supporting Information

S1 File: Minimal Dataset.
(DoCX)

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Author Contributions

Conceived and designed the experiments: MT CE CW RW MF TF AG SG. Performed the experiments: MT CE CW RW SG. Analyzed the data: MT CE CW RW MF TF AG SG. Contributed reagents/materials/analysis tools: MT CE CW RW MF TF AG SG. Wrote the paper: MT CE CW RW MF TF AG SG.

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Appendix A2

The Local Environment Model: an ecological approach to facilitating physical activity participation for children and youth with disabilities

This manuscript was submitted for publication in Disability and Rehabilitation, in October 2016, and is currently under review:


The Local Environment Model was designed by Dr Astrid Nyquist and Mr Inge Morisbak at BHC in 2007. The PhD candidate, Claire E Willis, was involved in the design and collation of data and information for this manuscript, and was the primary individual responsible for write-up.
Abstract

Purpose: The Local Environment Model (LEM) is an evidence-based program that facilitates physical activity participation for children and youth with disabilities. The aim of this paper was to provide a description of the LEM, to encourage implementation across contexts. Materials and methods: An implementation framework was employed, addressing the following criteria; (i) a clear description of the program (theoretical foundations, definitions of the target population, implementation drivers, and intervention protocol); (ii), theoretical core components of the program that must be present; and (iii), operational definitions that promote consistency across practitioners and resources. Results: Core components of the program were derived from adapted physical activity theory, situated learning theory and the International Classification of Functioning, Disability and Health, and included; activity-based, adapting environments and/or tasks, skilled professionals, group model, mutual engagement, and assessment and evaluation. Core implementation drivers are operationalised by staff selection and structure, facilitative administration and transformational leadership. Conclusion: This article provides a description of an ecological model that facilitates participation in physical activity for children with disabilities. It adds crucial support to the need to articulate effective programs in detail, to advance knowledge translation and evidence-based practice to improve outcomes for children and families.

Keywords: rehabilitation, environment, learning, community of practice, implementation
Introduction

Participation, defined as ‘involvement in a life situation’ [1], is a fundamental right of all children [2]. It is a core construct of the International Classification of Functioning, Disability and Health (ICF), a universally recognised framework that is utilised globally in rehabilitation [1]. The importance of participation to the World Health Organisation (WHO) Model of Disability [1], and hence rehabilitation research, is clear. As such, approaches to improving the participation outcomes of children with disabilities received considerable attention over the last 15 years. Empirical evidence and consumer priorities advocate the need to develop interventions that may assist in improving these outcomes [3, 4], which has been met with some success [5, 6]. However, health reports from around the world continue to criticise that not enough emphasis is being placed on the provision of opportunities for children and youth with disabilities participate in society as full community members [7-9]. The multidimensional impact of functional, environmental and personal factors on participation highlights the complexity of developing interventions that produce meaningful, long-term outcomes for the child and their family [10, 11].

Appropriate descriptions of rehabilitation programs and interventions are therefore crucial, from the earliest investigations of efficacy, to the ultimate applications in clinical care [12, 13]. Yet the many (and often overlapping) conceptual levels at which interventions operate, and the numerous theoretical orientations relevant to rehabilitation, can make this challenging [12]. As such, descriptions of specific interventions remain the least developed aspect of rehabilitation studies [12, 14]. This is reported as a significant weakness of current research [15, 16], and has a follow on effect to knowledge translation. The inability to comprehensively understand an evidence-based program can lead to overuse of unhelpful care, under-use of effective care, and errors in execution [17]. Rigorous definition of rehabilitation programs and interventions, supported by theory, will assist in successful implementation of effective programs into clinical practice [12, 13].

Beitostolen Healthsports Centre (BHC) is a rehabilitation centre in Norway, seeking to enhance lifelong activity and participation in local environments for people with disabilities. Using an ecological model [18], programs at BHC are designed to change the characteristics of the task and/or environment rather than the individual’s impairments, as a means of facilitating participation in physical, social and cultural activities in their communities. The BHC designed Local Environment Model (LEM) focuses on cooperation, education and resource capacity building in partnership with local communities, in order to facilitate continued participation in a child’s local environment [19-21]. Research examining the effectiveness of the intervention, and the transfer and maintenance of physical activity participation goals in a child’s local community,
showed encouraging results [22]. Both children and parents reported significant improvements in performance and satisfaction of participation goals following the intervention, and these remained significantly higher than baseline at 12 weeks follow-up [22]. Qualitative inquiry revealed that experiences at the rehabilitation centre enhanced the translation of outcomes into local environments of children and families [21].

The objective of this paper is to provide a clear description of the BHC rehabilitation model and LEM in practice, to foster implementation across rehabilitation disciplines, practitioners and consumers of paediatric rehabilitation. The model description articulates the resources, structures, services and evaluations required to bring about desired outcomes for each child and family. This paper is the first step in describing our service design and delivery, designed to act as an accompaniment to future articles that determine the active ingredients of the intervention in practice. Specifically, we aim to (i), provide a clear and detailed description of the LEM and intervention at BHC; (ii), describe the theoretically derived core components and their operational definitions; and (iii) outline implications for knowledge translation, program implementation, and future research.

Materials and methods:

A clear description of interventions is the first stage of implementation of evidence-based programs [23]. Criteria for defining a program has been developed by Fixsen et al. [23], and includes (i), a clear description of the program (including philosophies, values and theories that underlie the program and clear definitions of the population for which the program is intended); (ii), a clear description of core components of the program that must be present; and (iii), operational definitions of the core components that promote consistency across practitioners. For evidence-based programs to become a part of best clinical practice, they need to be clearly described so they can be taught, learned and implemented with good outcomes [23].

This article was written in accordance with the Template for Intervention Description and Replication (TIDieR) guidelines [13]. It will describe the LEM using the framework devised by Fixsen et al. [23], and will also describe the broader setting of the model. This includes health services, systems and policies in Norway; the healthsports centre and context in which it operates, and; the history of its development. Aspects of the environment at various levels [1, 18] influenced the development and implementation of the LEM (and so it’s operational definitions of the core components of the program), and we believe this information is required to clearly describe the LEM.
Results:

1. A clear description of the program

   a. National context: Health services, systems and policies

   In Norway, rehabilitation is defined as a ‘time limited, planned process with well-defined goals and measures, where several stakeholders collaborate to assist users in their own efforts to maximize functioning and coping capacities, independence and participation in society’ [24]. As such, patients have significant involvement in the development and implementation of their treatment plan, as outlined by the Patients’ Rights Act (1999) and the Public Health Act (2012) [25]. The Individual Care Plan (IP) was introduced by law in 2001, giving patients the right to receive managed and coordinated care and to be involved in the process of shaping their own services [24, 26]. An IP includes an outline of the patient’s objectives and resources as well as the services required, independent of diagnosis, age or level of care [27]. The IP is not a substitute for the patient record, but rather maps the patients’ needs and resources in health, finance, housing, social life, education and/or work [27]. Its main purpose is to define goals and tasks for selected areas, specify the responsible providers and indicate a schedule or timetable. This is a collaborative process that can mutually benefit, for example, a child with a disability across their home, health, educative and social life through cooperation across organisational boundaries [27]. Further, a number of services are available to assist in fostering an individuals’ independent function and social participation following rehabilitation. Municipalities are required by law to offer leisure support, personal assistance for individuals with disabilities to aid their participation in individual or group-based leisure activities [28]. Funding is readily available for assistive equipment and activity aids that are specifically designed to help people with disabilities to participate in physical activity (e.g. sitskis, specialised bikes, sports wheelchairs, orthotics etc.) [29].

   b. Philosophies, values and theoretical frameworks

   “Activity and participation throughout life” [30]

   BHC is recognised as an official part of the Norwegian national health system in physical medicine and rehabilitation. It is a distinctively Norwegian institution that addresses activity limitations and participation restrictions in adults and children with disabilities by means of adapted physical activity (APA). The term ‘healthsports’ is a national variant of the international term APA and, within rehabilitation at BHC, refers to facilitating participation in spite of
impairments and limitations, and not because of them. BHC provides services for children and adolescents (6-15 years), youth (16-25 years) and adults with a disability or chronic disease. Each year, approximately 500 children and adolescents (70% of the users) participate in a residential stay of three weeks at the centre.

The centre was established in 1970 by the blind visionary Erling Stordahl (1923-1994), and funded through a national telethon. Prior to this, Stordahl was using the land as a ski school for vision impaired individuals, and in 1964 initiated the Ridderrennet (the world’s largest disability ski event) [31, 32]. Stordahl’s inborn values and philosophies were paramount for the recognition of the full and rightful participation of people with disabilities in all life settings; “He devoted his life to help people, with and without disabilities, to befall their right to a full life – a life with challenges and joy - in the fight against their own inadequacies, against the anxiety and indifference of fellow citizens, and the societies’ institutionalised special treatment. More than anyone else, he has contributed to maturation of our society” (excerpt from the speech of The Minister of Culture, Åse Kleveland, on behalf of the Norwegian government at the funeral of Erling Stordahl, 1994).

Erling Stordahl served as the director of the centre from 1970-1994 [31]. The activities offered at the centre reflect the Norwegian culture, with a heavy emphasis on outdoor activities. Located in central Norway at the base of the Jotenheimen mountain range, the centre consists of living facilities, outdoor recreation facilities, swimming pools, a fitness training room, horse paddocks, a lake for water sports and fishing, hiking trails, cross country ski tracks and an alpine ski hill. Using the natural and built environment, the delivery of APA aims to enhance individual participation through the realisation of their own potential. Activities in the rehabilitation program have their own inherent value, in addition to their instrumental effects. Acquiring skills in adapted physical activities at BHC has been shown to facilitate participation in both activities of daily life and community-based physical activity, contributing to maintaining physical function in patients with physical impairments as their primary diagnosis [33].

Adapted Physical Activity

A term introduced in 1973 by the founders of the Federation Internationale de l’Activite Physique Adaptee [34], APA represents a core theoretical component of the rehabilitation program at BHC. The evolution of this concept has evoked many different definitions, interpretations and applications around the world. Broadly, APA can be defined as; (i), the body of knowledge that enables the creation of active living opportunities; (ii), a set of attitudes and behaviours that leads to the participation of people with a disability in sport and physical activity, and (iii), the adaptation of variables to facilitate the achievement of individuals aspirations in regard to movement outcomes, including attraction and support of exercise partners and making of friends.
through shared activity [34]. In contrast to therapies, APA is dedicated to the concepts of empowerment and ecological validity [35]. Physical activity implies more than development of motor skills and bodily competence; it offers the possibility to participate in social arenas and a cultural community [36]. Physical activity in rehabilitation may therefore open a passage for participation in social communities of life [36].

Rehabilitation practices at BHC align strongly with the underlying principles of APA. Rather than the impairment or the individual, the environment and society are considered modifiable barriers for participation in activity. Service delivery in APA is cooperative; the perspectives of participants are integrated into the planning and implantation of practices in a patient-centred approach. A primary focus of APA is ‘to support access to sport and active lifestyle, and develop cooperative home-school-community service delivery’ [37, p.136]. As with APA, BHC is dedicated to individualising instruction, matching personal interests with activities, and adapting environments to promote full participation in physical activity, regardless of the population being engaged [35].

Situated Learning and Communities of Practice

Situated learning theory posits that learning is unintentional and embedded in activity, context and culture [38]. A rehabilitation stay at BHC is primarily a learning process. Applying situated learning theory as the conceptual framework, Standal & Jespersen [39] investigated learning that takes place within an APA rehabilitation context at BHC. Results indicated that learning extended beyond skill acquisition and technique development, to include ways for the participants to make sense of their situation as wheelchair users [39]. Specifically, peers were identified as a learning resource; learning processes that took place between peers contributed to both self-development and the development of others [39].

Communities of practice is a theory of learning that starts with the assumption that engagement in social practice is the fundamental process by which we learn and so become who we are [40]. The concept of ‘communities of practice’ integrates the components of community, social practice, meaning and identity through mutual engagement, a joint enterprise and shared repertoire [40]. From this perspective, interaction and participation within the ‘community of practice’ of the Local Environment Model (LEM) at BHC provide the abilities to learn. The driving force in the learning process in a community of practice is the negotiation of meaning between its participants [41]. Prior to a stay at BHC, children, families and service providers face similar situations without the benefits of shared practice. The LEM, through the intervention at BHC, brings people together to explore their connectedness, negotiate their ‘community’ and
develop a ‘practice’. Following the stay at the centre, individuals no longer engage as intensely, yet each group continues to stay connected, and is utilised as a resource for knowledge, encouragement and facilitation of their participation upon their return home. The life cycle of a community of practice is determined by the value it provides to its members; thus, the aftermath of a stay for each LEM group is variable (figure 1).
Figure 1. The Local Environment Model as a Community of Practice
The International Classification of Functioning, Disability and Health

The ICF is a theoretical classification scheme devised by the WHO that offers a scientific tool for understanding human function and disability for clinical, research and other public health purposes [42]. The ICF defines health as a multi-dimensional concept, where a person’s functioning or disability is conceived as a dynamic interaction between health conditions and contextual factors [1]. One of the major innovations in ICF is the presence of environmental factors, a mandatory consideration in rehabilitation and the manipulated variable of programs at healthsports centres to enable participation. However, several shortcomings of the complex (yet crucial) domains of participation and contextual factors have been identified in the use of this framework, including inadequate conceptualisation and the subsequent effect on operationalisation and measurement of these domains [43, 44]. However, the ICF, continues to be a powerful international framework for understanding disability and health [45]. The ICF and ICF-CY is the theoretical framework used at BHC in coding the functional status of patients [46], assessing their needs and developing goals [46], measuring changes brought about by the intervention [21] and translating outcomes into their local communities.

c. Clear definition of the population for whom the program is intended

The inclusion criteria of the LEM are broad and non-specific. The LEM is intended for children and adolescents aged 6-17 years with activity limitations and participation restrictions (at home, school or in the community) identified by a medical practitioner. Children do not need to have a formal diagnosis to receive this service. Children can be referred to the LEM program by specialists, allied health professionals or identified by a rehabilitation unit. Rehabilitation services in local communities in Norway are responsible for putting together groups of 8-10 children, to then refer to BHC. There may be a range of diagnoses and ages within the group, depending on the community and need for this service. Specialised or homogenous diagnostic groups (e.g. rare diseases) are on occasion constructed.

d. Implementation drivers [47]

Competency drivers: There are approximately 100 staff employed at BHC. Personnel is divided into administrative (Director, chief of staff, information technology and reception), clinical services (allied health, pedagogical and medical), research and education (researchers and postgraduate research students), and support services (kitchen and maintenance). Additionally, service providers (physiotherapists, occupational therapists, teachers, teaching assistants etc.)
from participants’ local communities play fundamental roles in the preparation and follow-up components of the LEM.

BHC itself receives both national and international students for practicum at the centre. In cooperation with Norwegian School of Sports Sciences, BHC hosts part of formal studies in APA at the bachelor, master and doctoral level. Training (on-going), coaching and ‘learning by doing’ are the principle ways in which innovations to practice (and subsequent behaviour change) is brought about for the staff and students throughout the program. Furthermore, the role of didactics within clinical practice at BHC is significant. In Scandinavia, didactics forms a central component of the education of APA specialists and the subsequent delivery of programs [48]. At BHC, didactics refers to the relations between teaching, learning and socialisation. There is significant focus on professional self-reflection; thus, the quality of service delivery is continually being monitored at an individual level.

Organisational drivers: Clinical staff are divided into two major multidisciplinary rehabilitation teams; one for adults and one for children. There are five patient groups, each with an APA specialist, physiotherapist, and allied health assistant at its core. The staff teams of each group liaise daily with the medical specialists, social worker, occupational therapists, riding instructors, teachers and students working alongside users within the group. Rehabilitation programs and activity plans are developed in close cooperation with the teams and the users themselves, and organized and evaluated over time by the professional staff. Leisure-time activities (following the conclusion of the daily activity schedules, evening and weekends) are coordinated by a separate team. Together, this supports a child- and family-centred approach that embraces the child and family’s active involvement in the intervention. BHC is a facilitative administrative organisation [47], in which policies, procedures, culture and climate are given careful attention to ensure these aspects of the centre align with the needs of its staff.

Leadership drivers: Transformational leadership defines organisational behaviours at BHC [49]. Characteristics of transformational leadership include building identification with the leader’s vision, challenging followers to think differently, inspiring followers to extraordinary efforts, and building enough confidence in followers [50-52]. Following Erling Stordhal’s directorship, his values, attitudes and vision [31] are personified in subsequent leaders at BHC, and continue to be embodied by the centre’s staff [49].

e. Service delivery structure and intervention protocol: The Local Environment Model
The paediatric program at BHC is based upon a Local Environment Model (LEM) designed by researchers and staff at the centre in 2007. The model engages children, parents, professionals and local service providers in the preparation, intensive intervention and follow-up stages of service delivery (figure 1). The LEM is a group-based model that has specific focus on engaging local communities to facilitate a child’s physical activity participation in their home, school and community. Children and their families in each LEM group come from the same municipality in Norway. This means that before, during and after a rehabilitation stay at BHC, children and their families are connected (and can stay connected) with other children and families in their local communities [49].

**Stage 1: Preparation (in local communities)**

The LEM encompasses common preparation before the intervention at BHC. After confirming a group’s admission to the centre, a field team is responsible for establishing and maintaining contact with local communities and BHC. One month prior to the BHC intervention, the field team will travel to the community to meet the group coming to stay at BHC. The purpose of this meeting is to introduce BHC to the children and families; to familiarise them with the staff, facilities and program; to answer and questions and concerns of the parents and children; and to introduce the families to each other prior to their arrival. Local service providers of the child (physiotherapists, occupational therapists, teachers, teaching assistants) are also invited to attend a separate meeting, to promote a mutual understanding of the child’s program, encourage attendance at the course that BHC offers to service providers during the last week of the child’s stay, and to link local service providers to each other.

Prior to their arrival at the centre, children complete an electronic questionnaire called the ‘Children’s’. The ‘Children’s’ was developed by BHC as an adaptation of the Children’s Assessment of Participation and Enjoyment (CAPE) [53], and the Preference for Activities of Children (PAC) [54]. This consists of 19 activities, and using coloured faces, children indicate their desire to participate in these activities during their stay. Each child’s questionnaire results guide their initial goal setting interview, giving the teams at BHC an indication of the child’s preferences, current activity participation and potential goals.

**Stage 2: Intervention (at BHC)**

*Child:* Children are interviewed by a medical doctor and a multidisciplinary team of allied health professionals on arrival. Using the Canadian Occupational Performance Measure (COPM) [55], children make a goal-oriented plan for the stay at BHC. The three-week activity program of each
group is tailored to accommodate the goals and interests of each child. A child’s goals and rehabilitation plan are continuously monitored and adjusted when necessary.

The rehabilitation program includes physical, social and cultural activities, and extensive use of the outdoor facilities. These activities are facilitated for all children and adolescents, by changing aspects of the environment, providing assistive technology, and/or individual instruction. The program is intensive, with 2-5hrs of organised physical activities a day, 6 days a week, for 3 weeks. Parts of the program are based on the child’s goals, and parts are focused on introducing/exposing them to different physical activities and participation experiences (e.g. rock climbing). During the final days of the stay, children meet again with their team contact person to debrief about their stay, rescore the COPM and create a plan for their participation upon their return home. COPM goals are input into the Goal Attainment Scale (GAS) to measure attainment of physical activity participation goals in local community settings [56, 57].

Parents and siblings: All children who complete a stay at the center must be accompanied by a parent or guardian. Parents and/or guardians that stay can claim this as carers leave through their workplace. Parents actively participate in some (but not all) of the activities in their child’s weekly program. In addition, parents participate in their own specially designed ‘Parental Guidance Program’. The program is designed to emphasise the role of parents as facilitators to their child’s participation. The parental guidance program extends over the entire three-week period the child is at the center. During some stays, week two of the program is assigned ‘Family Week’. In this week, whole families of paediatric patients are welcome to stay, providing both parents and siblings with different workshops and activities, and opportunities to participate in leisure time activities as a family.

Local service providers: Following their participation in the preparation meeting, service providers of each child are invited to attend a three day course at BHC. The course is held during the second or third week of a child’s stay, and aims to (i), provide knowledge and guidance to practitioners about how to adapt environments to facilitate participation in individual and group settings, via practical learning opportunities and observation; (ii), connect service providers from the same municipality to encourage collaboration, exchange experiences and share knowledge to enhance service provision opportunities; and (iii), act as a forum to encourage conversations between parents and professionals to develop realistic follow up plans, to enhance the chance of translational success. The course is conducted free of charge, but each municipality must cover travel expenses for practitioners and costs relating to substitute staff (e.g. teachers). A representative from the Norwegian Confederation of Sport is also at BHC during this time. The
role of this individual is to assist parents and families in linking to sport, recreation and leisure organisations in their communities on their return home.

**Stage 3 & 4: Follow up and continuation**

Three months after families return to their local communities, a field team from BHC travels for the follow up meeting for children and their parents, and service providers. The primary objective of this meeting is to review and plan. Photos from the group’s stay are shown, and children are encouraged to talk about their experience at the centre. Additionally, this meeting is used to map each child’s progress towards achievement of their follow up plan (and re-score GAS goals), discuss any barriers families may still be facing in accomplishing this, and attempt to provide immediate solutions. The region’s representative from the Norwegian Confederation of Sport is also present at this meeting, so any problems that cannot be resolved can be followed up by local communities.

The second objective of this meeting is to begin the plan for the child’s second stay at BHC. Given the activities that children participate in during summer/autumn and winter/spring are markedly different (e.g. hiking, cycling and swimming in summer, snow activities in the winter), this second stay is generally desired by children and families. This stay occurs approximately 1.5 years after the first, in the opposite season. Together, the group determine the dates of their next stay, and share their expectations, goals and future plans.

**2. Clear description of core components with operational definitions**

Table 1 summarises the theoretically derived core components of the LEM intervention. Defining interventions on theoretical grounds allows specification of core dimensions of the treatment when operationally defining it [12]. Secondly, results of efficacy studies not only provide the empirical results of the effectiveness of the intervention; they also support or refute the theory(s) [12]. The core components of interventions are described as these must be present to say the program exists in a given location [23]. As such, operational definitions exist as ‘practice profiles’, to allow the program to be teachable, learnable and doable in in other settings [23] (table 1).
Table 1. Theoretically-derived core components of the Local Environment Model intervention

<table>
<thead>
<tr>
<th>Driving theoretical framework</th>
<th>Core components of LEM intervention</th>
<th>Operational definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adapted Physical Activity [34, 36]</td>
<td>Activity-based</td>
<td>Physical activities are adapted to the specific needs and abilities of individuals. A balance between challenging abilities and ensuring the child has the possibility to participate in social arenas and a cultural community. Improvements in functional capacities are regarded as complementary outcomes. 2-5hrs of activity each day (36-90hrs within the intervention).</td>
</tr>
<tr>
<td>Adapting environments and/or tasks.</td>
<td></td>
<td>Facilitating activities by changing aspects of the environment (including the learning environment), delivery of instruction and/or providing assistive equipment (e.g. sit skis, modified bikes).</td>
</tr>
<tr>
<td>Skilled professionals</td>
<td></td>
<td>Specific staff selection, ongoing training and coaching, self-reflection. A facilitative administration. Transformational leadership.</td>
</tr>
<tr>
<td>Situated learning [38] and communities of practice [40]</td>
<td>Group model</td>
<td>Individuals are active participants in a social environment and construct identities in relation to this community. Peers are a resource for learning. Children and their families reside in the same geographical area.</td>
</tr>
<tr>
<td>Mutual engagement</td>
<td></td>
<td>Common preparation, intervention and follow-up with local communities to promote shared and sustainable practice. Education and training provided to local service providers and parents cooperatively.</td>
</tr>
<tr>
<td>International Classification of Function, Disability and Health [1]</td>
<td>Assessment and evaluation</td>
<td>Tailored code set for the goal setting process, taking into account both child and family preferences and the health professionals’ perspective. Identification, intervention and follow up of constraints and facilitators related to the task and environment in child’s local community.</td>
</tr>
</tbody>
</table>

LEM, Local Environment Model.
3. Implications for translation, implementation and future research

A child’s stay at BHC is considered an integral link in the rehabilitation process in Norway, with the LEM employed nationwide. This model allows the intensive stay at BHC to translate to participation in physical activities in local communities of children and their families [22]. Being given the opportunity to choose their activities, to improve their skills and to experience mastering enjoyable activities with their friends, were identified by children as significant contributors to facilitating the translation of skills and maintenance of outcomes [21]. Barriers to goal attainment in the child’s local community were primarily environmental (e.g. access to services and equipment, lack of support and climate) [22]. These factors should be considered and addressed in future intervention design.

The uniqueness of our setting must be highlighted. Given the structure of most health care systems around the world, exact replication of this model would not be a feasible venture. Rather, the contribution of this paper is a clear description of a theory driven, evidence-based program that is successful in creating and maintaining change within complex domains of participation and the environment. Theoretically derived core components provide a description of the features of the LEM intervention that must be present, and should guide implementation to other locations. Cross cultural adaptations of finance models [58], international marketing [59] and products and services [60], all indicate the significant influence of both cultural and economic factors that impact conceptualisation, operationalisation and public understanding of a model in practice in new geographical settings. Thus, a comprehensive understanding of the environment (individual and societal) is essential for successful implementation [1, 18, 23]. It is with this in mind that we recommend following the implementation framework for evidence-based programs developed by Fixsen et al. [23, 47]. This is an active implementation process that incorporates best practices in relation to its four stages (exploration, installation, initial implementation and full implementation) and core implementation drivers (competency, organisation and leadership). The data supporting this framework and its application in multiple settings have been described in detail [61, 62], evidence that effective interventions combined with effective implementation result in improved outcomes.

The ICF has had a significant impact on the conceptualisation of disability and health. In rehabilitation, we use this framework to guide our definition and measurement of health and functional status, evaluation of individuals, interventions and services, and the development of policies [1]. Ultimately, the ICF provides a standard, universally-recognised classification system that makes it possible to collect interdisciplinary data in a consistent and internationally comparable manner [1]. With the adoption of the ICF and ICF-CY in rehabilitation research, we
have a globally agreed on a structure and common language that can be used to guide the translation of knowledge into clinical practice. This concept should therefore also apply when we consider the translation of effective interventions and service provision models across countries, cultures and disciplines.

Future research should examine the impact of cultural adaptations that enhance acceptability in cross-cultural translation, without undermining the theoretically-derived core components of this intervention. As replications of this intervention are unlikely to be undertaken in an institutionalised setting, it will be essential to understand the impact of implementing the model in another type of residential environment, and/or a ‘come-and-go’ program, on the outcomes of the intervention (e.g. goal attainment, social outcomes). A large part of a family’s stay at BHC consists of leisure time, periods that impact the overall experience of participants in the LEM intervention. As such, the context in which this intervention is trialled should be carefully considered.

Conclusion

This model of service within the Norwegian health system has been operating for decades. The LEM incorporates concepts of participation and the environment within intervention of whose importance are only now surfacing in paediatric rehabilitation literature. This article adds crucial support to the need to describe interventions and service delivery models in detail; without them, it is a limitation that constrains the advancement of evidence-based practice.

This article provides a description of a unique ecological model that is based on theories lying at the heart of education, rehabilitation and health promotion, to facilitate participation for children and youth with disabilities. The LEM encompasses strong theoretical foundations, linking intervention development to the evaluation of outcomes. This article provides a detailed and clear description of the LEM intervention, its core components and operational definitions to provide a comprehensive outline of an intervention that improves physical activity participation outcomes of children and adolescents with disabilities. It is our hope that other health-care providers are encouraged to try this approach.

Acknowledgments

We wish to thank Associate Professor Sonya Girdler and Mr Tor Erik Nyquist for their valuable discussion and advice throughout the writing of this manuscript. A Princess Margaret Hospital Foundation scholarship supported the second authors’ time compiling this article.
References


Nyquist AJ. Jeg kan delta!: Barn med funksjonsnedsettelser og deltagelse i fysisk aktivitet-en multimetodestudie i en habiliteringskontext [I can participate!: Children with disabilities and participation in physical activity - a multimethod study in a habilitation context] [PhD Thesis]. Oslo: Norwegian School of Sport Sciences; 2012.


Helse- og omsorgsdepartementet. Forskrift om habilitering og rehabilitering, individuell plan og koordinator. [regulations on habilitation and rehabilitation, individual plans and coordinator]. Oslo: Lovdata [Law data]; 2012.


Appendix B1

Knowledge Translation Plan
**Knowledge Translation Planning Template**

**INSTRUCTIONS:** This template was designed to assist with the development of Knowledge Translation (KT) plans for research but can be used to plan for non-research projects. The Knowledge Translation Planning Template is universally applicable to areas beyond health. Begin with box #1 and work through to box #13 to address the essential components of the KT planning process.

<table>
<thead>
<tr>
<th>(1) Project Partners</th>
<th>(2) Degree of Partner Engagement</th>
<th>(3) Partner(s) Roles</th>
<th>(4) KT Expertise on Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>researchers</td>
<td>from idea formulation straight through after idea formulation &amp; straight through at point of dissemination &amp; project end beyond the project</td>
<td></td>
<td></td>
</tr>
<tr>
<td>consumers - patients/families</td>
<td>Consider: Not all partners will be engaged at the same point in time. Some will be collaborators, end users or audiences, or people hired to do specific activities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the public</td>
<td></td>
<td>(1) What do the partner(s) bring to the project?</td>
<td></td>
</tr>
<tr>
<td>decision makers</td>
<td></td>
<td>(2) How will partner(s) assist with developing, implementing or evaluating the KT plan?</td>
<td></td>
</tr>
<tr>
<td>private sector/industry</td>
<td>Action: Capture their specific roles in letters of support to funders, if requested.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>research funding body</td>
<td></td>
<td>See Notes Section</td>
<td></td>
</tr>
<tr>
<td>volunteer health sector/NGO</td>
<td></td>
<td>scientists(s) with KT expertise</td>
<td></td>
</tr>
<tr>
<td>practitioners</td>
<td></td>
<td>consultant with KT expertise</td>
<td></td>
</tr>
<tr>
<td>other</td>
<td></td>
<td>knowledge broker/specialist</td>
<td></td>
</tr>
</tbody>
</table>

(1). What do the partners bring to the project?

Consumers, the public, decision makers, health sector, volunteers and practitioners will:
- act as a liaison between community members, consumer organisations and the research team.
- advocate on behalf of consumers and the community.
- ensure the relevance of each stage of the research (design, methods, data collection, analysis, dissemination and KT strategies), so that it is accurately addressing the needs of the community.

Researchers will:
- provide scientific expertise in the design, methods, data collection, analysis, dissemination and KT strategies.

(2). How will partners assist with implementing the KT plan?

All partners will be involved in the design, methods, data collection, analysis, dissemination and KT stages of the research. Consumers and the community will adapt knowledge to local contexts, assist in addressing barriers and facilitators to implementation, and select and tailor an intervention for local settings.

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1. Have you included any audiences on your research team?
   Yes. All have been included and will operate as a steering committee at all stages of the research process.

2. SMI: Consumers and the community gain knowledge and understanding of how to enhance participation outcomes for children and youth with disabilities.
### KT Process

When will KT occur?

- **Integrated KT**: Researchers and research users will collaborate to shape the research process, e.g., setting the research questions, deciding the methodology, involvement in data collection and tools development, interpretation of findings and dissemination of research results.

- **End of grant KT**: KT undertaken at the completion of the research process.

- **Both**

Comment on the specifics of your KT procedures; describe how you are using KT:

See notes

### KT Impact & Evaluation

#### (a) Where do you want to have an Impact?
- Healthcare/well-being outcomes
- Clinical practice
- Policies/systems
- Knowledge & awareness

#### (b) How will you know if you achieved your KT goal(s)? Consider:
- Reach indicators (i.e., distributed, requested, downloads/hits, media exposure)
- Utilization indicator (read/browsed, satisfied with, usefulness of, gained knowledge, changed views)
- Use indicators (if intend to use, if adopting the information, if using to inform policy/advocacy/endeavor programs, training, education, or research, if using to improve practice or performance)
- Partnership/collaboration indicators (if products/services developed or disseminated with partners, if or type capacity building efforts, shared network growth, influence, collaboration)
- Practice change indicators (intend or commitment to change, observed change, reported change)
- Program or service indicators (outcome data, documentation, feedback, process measures)
- Policy indicators (documentation, feedback, process measures)
- Knowledge change (quantitative & qualitative measures)
- Attitude change (quantitative & qualitative measures)
- Systems change (quantitative & qualitative measures)

#### (c) Guiding Questions for Evaluation

1. What internal/external factors do you need to consider? Where is the design for this work? How have similar initiatives been evaluated in the past? (link this to partners, KUs)
2. Who leads the evaluation of this initiative? What are they saying they want from this evaluation? (link this to partners, KUs)
3. Why are you evaluating? For program growth or improvement, accountability? Sustainability? Knowledge generation? (e.g., to know if the KT strategy met the objectives)
4. How will literature or existing theories inform how you evaluate the initiative?
5. Which questions/objectives are critical? (link this to KT goals, process, impact)
6. Will you focus on process or outcomes information? What are your pre-determined outcomes? How will you capture emergent outcomes?

Using a steering committee comprising of key knowledge users, this group will collaborate with the research team across varying stages of the research cycle. Interactive small group meetings will be held at the development, analysis and dissemination stages of each study. Task-based activities and group discussions will be the primary procedures used in collaboration to shape the research process.

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### Resources

- board
- financial
- human
- IT
- leadership
- management
- volunteer
- web
- writer
- other: (list)

### Budget Items

- accommodation
- art installation
- evaluation specialist
- graphics/imagery
- knowledge broker
- KT specialist
- mailing
- media release
- media product (e.g., video)
- networking functions
- open access journal
- plain text writer

**Estimated costs for items listed**

- $3000AUD

**NOTE** Be sure to include all KT costs in your budget for funders

### Implementation

**Describe how you will implement your KT strategy(s):**

What processes/procedures are involved? If practice or behaviour change is the focus, how will you ensure the knowledge (intervention) you are transferring retains quality, fidelity, sustainability?

**See notes**

---

Using a steering committee comprising of key knowledge users, this group will collaborate with the research team across varying stages of the research cycle. Each study within the project will address the three stages in the Knowledge Funnel, and adapt knowledge to local contexts in the Knowledge-To-Action Cycle. Following this, barriers and facilitators will be addressed, and the steering group will assist in the tailoring of the final intervention to the local context.

Results from all research will also be disseminated using infographics and media. All KT supplements will be developed in collaboration with the steering group. Infographics will be sent to the graphic design team at PHM for complete development. These will be disseminated to knowledge users through professional networks, hospital newsletter and emails, university media releases, and be delivered to consumers by the researchers and/or clinical teams during clinic appointments. Future development of the research outcomes into short animations for health professionals and consumers is planned. Future research will monitor and evaluate outcomes, both of the research and the translation of knowledge.


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Appendix B2

Plain language infographics for consumers and health professionals
GETTING KIDS WITH DISABILITIES ACTIVE! A guide for health professionals

Participation in physical activity is important for young people’s health
Children with disabilities are less active than their typically developing peers

How can health professionals support their involvement in physical activity?

DEVELOP INTERVENTIONS THAT ARE:

- Group-based 8-10 children of similar ages and a range of abilities
- Activity-based A variety of physical activities, 36-72hrs total dosage
- Goal (child)-directed Children can express their needs, hopes and goals

- Family-centred Parents and siblings can join in some (not all) activities
- Mutual engagement and community cooperation with resources and services

- Multidisciplinary teams made up of exercise specialists & other allied health professionals
- Evaluation of the intervention, the environment, and barriers and facilitators
- Support networks for health professionals, families and children

WHAT ABOUT THE ENVIRONMENT?

- The built and natural environment is accessible
- Appropriate equipment is available
- Create a community of people
- Consider the lifespan

What can you do?

1. Use a strengths-based approach
2. Focus on changing the task and/or environment, rather than the child or youth
3. Have a clear vision, with strong leadership

How do we know this? 20 staff and service providers involved in a physical activity participation program for children and youth with disabilities participated in our study. Please contact: Claire.willis@health.wa.gov.au
Children and youth with disabilities tell us about participating in physical activity

To participate, I need:

A place where...
- I feel safe
- I have new activities to learn
- My family is there (sometimes)
- There are children like me

I can...
- Make choices
- Have fun
- Make friends
- Take as much time as I need,
- And people know how to help

So then...
- I achieve my goals,
- And even think of more!
- I enjoy physical activity
- I do things on my own

WHY DO WE NEED TO KNOW THIS?
Participating in regular physical activity is important for everyone. For lots of reasons, being active can sometimes be hard for children and adolescents with disabilities. This information can help people understand what children need to be able to participate.

HOW CAN I USE THIS?
As a health professional: This may support your approach to helping a child achieve their physical activity participation goals.

As a parent: This might help you, and other supervising adults, to know what your child needs to participate in activities meaningful to them.

As a child or adolescent with a disability: Sometimes it is hard to talk about what you need. This might help you tell people what you need to be able to participate.
Children and youth with disabilities spend 76% to 99% of their time awake in sedentary activity.

Participation in physical activity is necessary for the best possible development of all children and youth. Parents play an influential role as barriers and facilitators to a child’s participation physical activity.

How can you support parents to help their child participate?

- Involve parents in some parts of the intervention
- Make PARTICIPATION the focus of the intervention
- Parents and children can participate in a range of activities with people who can help
- Families can meet other families from the same community
- Parents have support before, during, and after the intervention
- There is support for changes in activity preferences as the child grows up

Parents LEARN and are EMPOWERED

Ongoing participation in physical activity for families

For more information, please contact: Claire.wills@health.wa.gov.au
# APPENDIX C: SCOPING REVIEW QUALITY ASSESSMENT CHECKLIST

## Checklist for qualitative studies:

<table>
<thead>
<tr>
<th>#</th>
<th>Criteria</th>
<th>Yes (2)</th>
<th>Partial (1)</th>
<th>No (0)</th>
<th>n/a</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Question/objective sufficiently described?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Study design evident and appropriate?</td>
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<td></td>
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</tr>
<tr>
<td>3</td>
<td>Context of the study clear?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>4</td>
<td>Connection to theoretical framework/wider body of knowledge?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Sampling strategy described, relevant and justified?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Data collection methods clearly described and systematic?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7</td>
<td>Data analysis clearly described and systematic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Use of verification procedure(s) to establish credibility?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Conclusion supported by results?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>10</td>
<td>Reflexivity of the account?</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

|    | Total:                                                                  |         |             |        |     |


APPENDIX D: ETHICS APPROVALS

Appendix D1

Princess Margaret Hospital Ethics Approval
Dear Dr Valentine

HUMAN RESEARCH ETHICS COMMITTEE (HREC)

HREC REF 2013099EP

STUDY TITLE The 'Participate' Study: Preparing children with Acquired Brain Injury for integration into community recreation and leisure activity

The ethics application for the project referenced above was reviewed by the PMH Human Research Ethics Committee (HREC) at its meeting on 17/10/2013. It has been approved and the following documents have been approved for use in this project.

Forms 1A, 2A, 4B, Information Sheets Adult, Parent & Child, Questionnaires

Approval of this project from PMH HREC is valid to 17/10/2016 and on the basis of compliance with the Conditions of HREC Approval for a Research Project (attached).

[Note: If additional sites are recruited prior to the commencement of, or during the research project, the Coordinating Principal Investigator is required to notify the HREC. Notification of withdrawn sites should also be provided to the HREC in a timely fashion.]

A copy of this ethical approval letter must be submitted by all site Principal Investigators to the Research Governance Office or equivalent body or individual at each participating institution in a timely manner to enable the institution to authorise the commencement of the project at its site/s.

This letter constitutes ethical approval only.

This project cannot proceed at any site until separate site authorisation has been obtained from the CE, or delegate, of the site under whose auspices the research will be conducted at that site.

The PMH HREC is registered with the Australian Health Ethics Committee and operates according to the NHMRC National Statement on Ethical Conduct in Human Research and International Conference on Harmonisation – Good Clinical Practice.

The HREC’s Terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.pmh.health.wa.gov.au/development/resources/ethics.htm or from the Ethics Office. Should you have any queries about the HREC’s consideration of your project, please contact Ethics Office.
Please quote the above trial number 2013099EP on all correspondence associated with this trial.

Yours sincerely

[Redacted]

Dr Mark Suttor
Executive Director
Medical Service

21/11/2013

* The Ethics Committee is constituted, and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Research Involving Humans
Dr Jane Valentine  
Dept Paediatric Rehabilitation  
PMH  
Subiaco 6008

Dear Dr Valentine

**HRMC REF**  2013099EP  
**STUDY TITLE**  The 'Participate' Study: Preparing children with Acquired Brain Injury for integration into community recreation and leisure activity

On behalf of the Child and Adolescent Health Service, I give authorisation for your research project to be conducted at the following site(s):

PMH

The following site specific documents are to be used in addition to those approved by the Human Research Ethics Committee (HRMC).

Form 1A  
Form 2A  

This authorisation is based on the approval from PMH HREC and the review from the Research Governance Office. This authorisation is valid subject to the ongoing approval from the HREC.

This authorisation is based on the ethical approval from the HREC, and on the basis of compliance with the 'Conditions of Authorisation to Conduct a Research Project at Site' (attached) and with the compliance of all reports as required by the Research Governance Office and approving HREC. Non compliance with these requirements could result in the authorisation being withdrawn.

The responsibility for the conduct of this project remains with you as the Principal Investigator at the site.

Yours sincerely

[Signature]

Dr Mark Salmon  
Executive Director  
Medical Service  
22/10/2013
Appendix D2

The University of Western Australia Ethics Approval

Our Ref: RA/4/1/6556

04 December 2013

Assistant Professor Siobhan Reid
School of Sport Science, Exercise & Health
MBDP: M408

Dear Professor Reid

HUMAN RESEARCH ETHICS OFFICE – RECOGNITION OF ETHICS APPROVAL FROM ANOTHER HUMAN RESEARCH ETHICS COMMITTEE

Project: The Participate Study: Preparing Children with Acquired Brain Injury for Integration Into Community Recreation & Leisure Activity - Recognition of PMH HEC approval 2013099EP

Thank you for your correspondence enclosing the necessary documents to facilitate recognition of the ethics approval for the above project granted by an external Human Research Ethics Committee (HREC) registered with the National Health and Medical Research Council (NHMRC).

It is noted that you have ethics approval from Princess Margaret Hospital, approval number 2013099EP.

The UWA students and researchers identified as working on this project are:

UWA Researchers:

<table>
<thead>
<tr>
<th>Name</th>
<th>Faculty / School</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistant Professor Siobhan Reid</td>
<td>School of Sport Science, Exercise &amp; Health</td>
<td>Chief Investigator</td>
</tr>
<tr>
<td>Associate Professor Michael Rosenberg</td>
<td>School of Sport Science, Exercise &amp; Health</td>
<td>Co-Investigator</td>
</tr>
</tbody>
</table>

Student(s): Clare Willis - PhD - 20247083

Although The University of Western Australia reserves the right to subject any research involving its staff and students to its own ethics review process, in this case the Human Research Ethics Office has recognised the existing approval of the external HREC. The project is exempt from ethics review at UWA and the involvement of the above-listed researchers has been authorised. Any conditions for the recognition of the external HREC's existing approval are listed below:

Special Conditions

None specified

You are reminded that it will be the responsibility of the approving HREC to ensure compliance with all ethics requirements and to monitor and report on the project. However, should any relevant ethics issues arise during the course of the project, you should inform the Human Research Ethics Office of The University of Western Australia.

If you have any queries, please contact the HREO at hreo-research@uwa.edu.au.

Please ensure that you quote the file reference – RA/4/1/6556 – and the associated project title in all future correspondence.

Yours sincerely,

Dr Mark Dixon
Associate Director, Research Ethics and Biosafety

Research Ethics and Biosafety Office
Research Services
Phone: +61 8 6488 4703
Fax: +61 8 6488 8775
Email: hrec-research@uwa.edu.au
MBDP: M459
Our Ref: RA/4/1/8203

22 April 2010

Dr Siobhan Reid
School of Sport Science, Exercise and Health
M8DP, M4QB

Dear Doctor Reid

HUMAN RESEARCH ETHICS OFFICE – EXEMPTION FROM ETHICS REVIEW

Enabling physical activity participation for children with disabilities: Goal attainment, performance, and satisfaction.

Student(s):

Based on the information you have provided to the Human Ethics Office in relation to the above project, the described activity has been assessed as exempt from ethics review at the University of Western Australia.

However, should there be any significant changes to the protocol, you must contact the HREO to determine whether your exempt status remains valid or whether you will be required to submit an application for ethics approval.

If you have any queries please contact the Human Ethics office at humanethics@uwa.edu.au.

Please ensure that you quote the file reference – RA/4/1/8203 – and the associated project title in all future correspondence.

Yours sincerely

Dr Celia Li
Manager, Human Ethics
Appendix D3

Norwegian Regional Ethics Committee Section South East Ethics Approval

Framleggsvurdering  Skjema for vurdering av framleggingsplikt i de regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK)

2014/1342-1
Dokument-id: 513443 Dokument mottatt 15.08.2014

To Claire Willis.

With reference to the abovementioned study, and your question as to whether this study requires an ethical approval from a Norwegian REC, received 15th of August 2014:

The ethics committee system consists of seven independent regional committees, with authority to either approve or disapprove medical research studies conducted within Norway, or by Norwegian institutions, in accordance with ACT 2008-06-20 no. 44: Act on medical and health research (the Health Research Act).

The abovementioned study - A case study of a Norwegian rehabilitation model - is exempt from review in Norway, cf. §§ 2 and 9 of The Act. The project can be implemented without the approval by the Regional Committee for Medical Research Ethics.

Please do not hesitate to contact the Regional Committee for Medical and Health Research Ethics, section South-East C (REK Sør-Øst C) if further information is required.

Yours sincerely,

--
Tor Even Svanes
Senior Advisor

Regional komité for medisinsk og helsefaglig forskningsetikk, Sør-Øst C
Postboks 1130 Blindern, 0318 Oslo. Tlf: 22 84 55 21
Besøksadresse: Nydalen Allé 37b, Nydalen, 0424 Oslo.
http://helseforskning.etikkom.no
APPENDIX E: PARTICIPANT INFORMATION AND CONSENT FORMS

Appendix E1

Information Sheet for Beitostolen Healthsports Centre Staff

PARTICIPANT INFORMATION SHEET

A case study of a Norwegian rehabilitation model: Identifying elements of success

Why are we doing the study?
Beito
stolen Healthsports Centre is an international leader in Adapted Physical Activity, providing standards of best practice in this field. Regular participation in physical activity helps children with disabilities to improve and maintain their physical and mental health, enhances outcomes at school and encourages the development of friendships.

This study is looking to identify the parts of the program at Beitostolen Healthsports Centre that make it so successful in integrating children with disabilities in recreation and leisure activities. We would also like to identify the elements of the program that may be possible to implement in Australia. To do this, we require you to take part in an interview about Beitostolen Healthsports Centre, the programs you are a part of and the effect this has on the children and families that participate in a stay.

Who is carrying out the study?
This study is being carried out by researchers in Australia, and researchers at Beitostolen Healthsports Centre. The researchers from Australia are from the Department of Paediatric Rehabilitation at Princess Margaret Hospital, and the School of Sport Science, Exercise and Health at the University of Western Australia.

What will the study tell us?
This study will help us to understand the elements of the BHC model that make it a successful program. This study will provide us with important information about how we can best develop a similar program for children in Australia.

Do I have to take part?
No, your participation in this research is voluntary and you are free to withdraw from the study at any time, for any reason, without prejudice in any way. You need not give a reason or justification for such a decision. Should you withdraw from the research, records will be destroyed.
What will you be asked to do if you decide to take part in this study?
Your participation in this study will require you to participate in an interview. A translator will be present for the duration of the interview. You will be asked questions about the children’s program at Beitostolen Healthsports Centre, and the long-term effects of this on children and their families. The interview will take less than an hour and will take place in a conference room at a time convenient to you.

What does this organisation need to do to be in the study?
If you meet the following criteria, you are eligible to participate in this study:
- You have been employed at Beitostolen Healthsports Centre for at least 1 year
- You are directly involved in the provision of services to children

Is there likely to be a benefit to me?
The information obtained from the interviews may be able to enhance the program at BHC, and may increase the international exposure of the Centre.

Is there likely to be a benefit to other people in the future?
The information we obtain in this study is part of a research project that is aiming to develop a program similar to BHC for children in Australia. Your participation will provide us with vital information that will help prepare Australian children with disabilities for participation in community recreation and leisure activities. This research has the potential to enhance the participation opportunities and quality of life of children and their families in Australia.

What are the possible risks and/or side effects?
The participation in an interview poses no risk to you or Beitostolen Healthsports Centre. All data will be coded so as to preserve the identity and confidentiality of you and the organisation.

What are the possible discomforts and/or inconveniences?
Participation in the interview may take up to an hour of your time. This will not affect your work and will not occur during times when you have sessions with children and families.

Where is your information kept?
All information is kept on a password secured computer in the private office of the investigator at BHC. This office is locked at all times when not in use and is only accessible by the researcher.

What about my privacy?
Participant confidentiality will be respected at all times. The results of this research may be published, however no identifying information shall be revealed. All data will be coded so as to preserve the identity and confidentiality of you and your organisation.

Who has approved the study?
The Princess Margaret Hospital Ethics committee has approved this research.

Who to contact if you have any concerns about the organisation or running of the study?
If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: 011 61 8 9340 8222). Your
concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

**What to do next if you would like to take part in this research:**
If you would like to take part in this research study, please read and sign the consent form provided.

**Who to contact for more information about this study:**
If you would like any more information about this study, please do not hesitate to contact one of the research team. They are very happy to answer your questions.

**Dr Jane Valentine**  
Chief Investigator  
Princess Margaret Hospital  
00 61 8 9340 8886  
Jane.Valentine@health.wa.gov.au

**Dr Catherine Elliott**  
Associate Investigator  
Princess Margaret Hospital  
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**Dr Siobhan Reid**  
Associate Investigator  
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**Dr Michael Rosenberg**  
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**Dr Sonya Girdler**  
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**Dr Anna Gubbay**  
Associate Investigator  
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00 61 8 9340 8886  
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reijah@ous-hf.no

**Dr Astrid Nyquist**  
Associate Investigator  
Beitostolen Healthsports Centre, Norway  
61 34 08 00  
astrid.nyquist@bhss.no

**Claire Willis**  
Associate Investigator  
University of Western Australia  
00 61 8 9380 2128  
claire.willis@health.wa.gov.au

**THANK YOU FOR YOUR TIME**
PARTICIPANT INFORMATION SHEET

A case study of a Norwegian rehabilitation model: Identifying elements of success

Why are we doing the study?
Beitostolen Healthsports Centre (BHSS) is an international leader in Adapted Physical Activity, providing standards of best practice in this field. This study is looking to identify the parts of the program at BHSS that make it so successful in integrating children with disabilities in recreation and leisure activities. We would also like to identify the elements of the program that may be possible to implement in Australia. To do this, it is also important that we involve the service providers in Norway, to find out how they are able to continue this work in their local communities. We require you to take part in an interview about your time at BHSS, and how this may impact the services you provide.

Who is carrying out the study?
This study is being carried out by researchers in Australia, and researchers at BHSS. The researchers from Australia are from the Department of Paediatric Rehabilitation at Princess Margaret Hospital, and the School of Sport Science, Exercise and Health at the University of Western Australia.

What will the study tell us?
This study will help us to understand the elements of the BHSS Local Environment Model that make it a successful program. This study will provide us with important information about how we can best develop a similar program for children in Australia.

Do I have to take part?
No, your participation in this research is voluntary and you are free to withdraw from the study at any time, for any reason, without prejudice in any way. You need not give a reason or justification for such a decision. Should you withdraw from the research, records will be destroyed.

What will you be asked to do if you decide to take part in this study?
Your participation in this study will require you to participate in an interview. A translator can be present for the duration of the interview. You will be asked questions about your experience at BHSS and how this will affect your practice in your own
community. The interview will take less than an hour and will take place in a conference room at a time convenient to you.

**What does this organisation need to do to be in the study?**
If you meet the following criteria, you are eligible to participate in this study:
- You have participated in a professional development workshop at BHSS.
- You are directly involved in the provision of services to a child/ren that are participation in a stay at BHSS.

**Is there likely to be a benefit to me?**
The information obtained from the interviews may be able to enhance the program at BHSS, which may directly affect you as a service provider in the child’s local community.

**Is there likely to be a benefit to other people in the future?**
The information we obtain in this study is part of a research project that is aiming to develop a program similar to BHSS for children in Australia. Your participation will provide us with vital information that will help prepare Australian children with disabilities for participation in community recreation and leisure activities. This research has the potential to enhance the participation opportunities and quality of life of children and their families in Australia.

**What are the possible risks and/or side effects?**
The participation in an interview poses no risk to you or BHSS. All data will be coded so as to preserve the identity and confidentiality of you and the organisation.

**What are the possible discomforts and/or inconveniences?**
Participation in the interview may take up to an hour of your time. This will not occur during times when you have professional development workshops or sessions with children and families.

**Where is your information kept?**
All information is kept on a password secured computer in the private office of the investigator at BHSS. This office is locked at all times when not in use and is only accessible by the researcher.

**What about my privacy?**
Participant confidentiality will be respected at all times. The results of this research may be published, however no identifying information shall be revealed. All data will be coded so as to preserve the identity and confidentiality of you and your organisation.

**Who has approved the study?**
The Princess Margaret Hospital Ethics committee has approved this research.

**Who to contact if you have any concerns about the organisation or running of the study?**
If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: 011 61 8 9340 8222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.
What to do next if you would like to take part in this research:
If you would like to take part in this research study, please read and sign the consent form provided.

Who to contact for more information about this study:
If you would like any more information about this study, please do not hesitate to contact one of the research team. They are very happy to answer your questions.

Dr Jane Valentine
Chief Investigator
Princess Margaret Hospital
00 61 8 9340 8886
Jane.Valentine@health.wa.gov.au

Dr Catherine Elliott
Associate Investigator
Princess Margaret Hospital
00 61 8 9340 8886
Catherine.Elliott@health.wa.gov.au

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Associate Investigator
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Dr Michael Rosenberg
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Dr Noula Gibson
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Dr Anna Gubbay
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anna.gubbay@health.wa.gov.au

Dr Reidun Jahnsen
Associate Investigator
Beitostolen Healthsports Centre, Norway
61 34 08 00
reijah@ous-hf.no

Dr Astrid Nyquist
Associate Investigator
Beitostolen Healthsports Centre, Norway
61 34 08 00
astrid.nyquist@bhss.no

Claire Willis
Associate Investigator
University of Western Australia
00 61 8 9380 2128
claire.willis@health.wa.gov.au

THANK YOU FOR YOUR TIME
INFORMASJON TIL FORELDRE

Om studien:
En casestudie av en norsk rehabiliteringsmodell: Identifisere suksessfaktorer

Hvorfor gjør vi studien?
Beitostølen Helsesportsenter (BHSS) er internasjonalt ledende innen tilpasset fysisk aktivitet, som gir standarder for beste praksis på dette feltet. Regelmessig deltagelse i fysisk aktivitet hjelper barn med funksjonsnedsettelser å forbedre og vedlikeholde deres fysiske og psykiske helse, forbedrer resultatene på skolen og oppmuntrer til utvikling av vennskap.

Denne studien søker å identifisere de delene av programmet på BHSS som bidrar til at barn med funksjonsnedsettelser i større grad deltar i rekreasjons- og fritidsaktiviteter. Vi ønsker også å identifisere de elementene i programmet som kan være mulig å gjennomføre i Australia. For å gjøre dette, kan vi be deg og barnet ditt om å ta del i et intervju eller en fokusgruppe for å fortelle oss om ditt opphold på BHSS, og hvordan dette kan ha en innvirkning på din familie og livsstil.

 Hvem er forskerne?
Denne studien blir utført av forskere i Australia og forskere på BHSS. Forskerne fra Australia er fra Department of Paediatric Rehabilitation på Princess Margaret Hospital (PMH), og School of Sport Science, Exercise and Health ved University of Western Australia (UWA).

Hva vil studien fortelle oss
Denne studien vil hjelpe oss til å forstå elementene i BHSS sin behandlingsmodell som bidrar til at barn med funksjonsnedsettelser i større grad deltar i rekreasjons- og fritidsaktiviteter. Denne studien vil gi oss viktig informasjon om hvordan vi best kan utvikle et lignende program for barn i Australia.

Frivillig deltagelse
Deltakelse i denne forskningen er frivillig, og du står fritt til å trekke deg og barnet ditt fra studien når som helst, uansett årsak. Du trenger ikke oppgi en forklaring for en slik beslutning. Skulle du trekke seg fra forskningen, vil registreringer av deg og barnet ditt bli slettet.

Hvis du trekker deg fra studien, vil dette ikke berøre deg eller barnet ditt sine rettigheter som bruker av BHSS.
Hva vil du bli bedt om å gjøre?
Din deltakelse i denne studien vil kreve at du og barnet ditt deltar i separate intervjuer under oppholdet. En oversetter kan være tilstede under hele intervjuet. Du vil bli stilt spørsmål om din erfaring med BHSS, og målsettinger som er satt under oppholdet som påvirker barnet og familien. Intervjuet vil ta mindre enn en time, og vil finne sted på BHSS på et tidspunkt som passer for deg.
Som en del av ditt barns opphold, vil du sammen med barnet ditt ha fullført Goal Attainment Scale (GAS). Dette er et ledd i rutinemessig praksis ved BHSS og er ikke en del av denne studien. Med ditt samtykke, vil denne studien bruke dataene fra GAS overvåke barnets oppnåelse av sine mål fra oppholdet.

Hva trenger barnet mitt å gjøre for å delta studien?
Ved å delta på et opphold på BHSS vil du og barnet ditt være kvalifisert til å delta i denne studien.

Er det sannsynlig å være en fordel for barnet mitt?
Den informasjonen vi får fra å fullføre GAS med barnet ditt vil være på fil ved BHSS for deres fremtidige programmering.

Vil informasjon fra studien være nyttig for andre mennesker i fremtiden?
Den informasjonen vi får i denne studien er en del av et forskningsprosjekt som har som mål å utvikle et program som ligner på BHSS for barn i Australia. Din deltakelse vil gi oss viktig informasjon som vil bidra til å hjelpe australske barn med nedsatt funksjonsevne til økt deltakelse i rekreasjons- og fritidsaktiviteter. Denne forskningen har potensial til å øke deltakelsesmuligheter og livskvalitet for barn og deres familier i Australia.

Hva er de mulige risikoer?
Deltakelse i et intervju utgjør ingen risiko for deg. Alle data vil bli kodet, for å bevare din konfidentialitet. Deltakelse i intervjuet kan ta opptil en time. Dette vil ikke påvirke noen del av ditt barns opphold, og vil ikke skje når det er planlagt spesielle informasjonsmøter, avtaler eller aktiviteter.

Hvor oppbevares din informasjon?
All informasjon oppbevares på en passord-sikret datamaskin på forskerens private kontor på BHSS.

Hva med personvernet?
Deltakernes konfidensialitet vil bli respektert til alle tider. Resultatene av denne forskningen kan bli publisert, men ingen opplysninger som kan identifisere deltakerne skal bli avslørt.

Hvem har godkjent studien?
De etiske komiteer på PMH og UWA har godkjent denne forskningen.

Hvem skal jeg kontakte om jeg har noen bekymringer om studien?
Hvis du har noen bekymringer eller klager angående denne studien, kan du kontakte Director of Medical Services på PMH (Telefonnummer: 011 61 8 9340 8222). Dine bekymringer vil meldes til Etikkutvalget som overvåker studien.

Hva skal jeg gjøre hvis jeg ønsker å ta del i denne forskningen?
Hvis du og ditt barn ønsker å ta del i denne forskningsstudien, kan du lese og signere samtykkeskjemaet.

**Hvem kan jeg kontakte for mer informasjon:**
Hvis du ønsker mer informasjon om denne studien, ikke nøl med å kontakte en fra forskerteamet. De er veldig glad for å svare på dine spørsmål.

**Dr Jane Valentine**
Chief Investigator
Princess Margaret Hospital
00 61 8 9340 8886
Jane.Valentine@health.wa.gov.au

**Dr Catherine Elliott**
Associate Investigator
Princess Margaret Hospital
00 61 8 9340 8886
Catherine.Elliott@health.wa.gov.au

**Dr Siobhan Reid**
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**Dr Astrid Nyquist**
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**Claire Willis**
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claire.willis@health.wa.gov.au

**TAKK FOR OPPMERKSOMHETEN**
Appendix E4
Parent Information Sheet (English)

PARENT INFORMATION SHEET

A case study of a Norwegian rehabilitation model: Identifying elements of success

Why are we doing the study?
Beitostolen Healthsports Centre is an international leader in Adapted Physical Activity, providing standards of best practice in this field. Regular participation in physical activity helps children with disabilities to improve and maintain their physical and mental health, enhances outcomes at school and encourages the development of friendships.

This study is looking to identify the parts of the program at Beitostolen Healthsports Centre that make it successful in helping children with disabilities participate in recreation and leisure activities. We would also like to identify the elements of the program that may be possible to implement in Australia. To do this, we require you and your child to take part in an interview to tell us about your stay at Beitostolen Healthsports Centre and how this may have an impact on your family and lifestyle.

Who is carrying out the study?
This study is being carried out by researchers in Australia, and researchers at Beitostolen Healthsports Centre. The researchers from Australia are from the Department of Paediatric Rehabilitation at Princess Margaret Hospital, and the School of Sport Science, Exercise and Health at the University of Western Australia.

What will the study tell us?
This study will help us to understand the elements of the BHC model that make it successful in helping children with disabilities participate in recreation and leisure activities. This study will provide us with important information about how we can best develop a similar program for children in Australia.

Does my child have to take part?
No, participation in this research is voluntary and you are free to withdraw you and your child from the study at any time, for any reason, without prejudice in any way. You need not give a reason or justification for such a decision. Should you withdraw from the research, records of you and your child will be destroyed.

If you withdraw from the study, this will not prejudice you or your child’s status and rights as a user of Beitostolen Healthsports Centre. Your participation in this study does
not prejudice any right to compensation, which you may have under the statute of common law.

**What will you be asked to do if you decide to take part in this study?**
Your participation in this study will require you and your child to participate in separate interviews towards the end of your stay. A translator will be present for the duration of the interview. You will be asked questions about your experience at Beitostolen Healthsports Centre, and your participation goals for your child and family. The interview will take less than an hour, and will take place in a conference room at BHC at a time convenient to you.

As a part of your child’s stay, you will have completed the Canadian Occupational Performance Measure (COPM). This is a part of routine practice at BHC and is not a part of this study. With your consent, this study will use the data from the COPM to follow up on your child’s experience at BHC.

**What does my child need to do to be in the study?**
By participating in a stay at BHC, you and your child are eligible to participate in this study.

**Is there likely to be a benefit to my child?**
The information obtained from completing the Canadian Occupational Performance Measure with your child will be on record at BHC for future reference for your child’s clinician.

**Is there likely to be a benefit to other people in the future?**
The information we obtain in this study is part of a research project that is aiming to develop a program similar to BHC for children in Australia. Your participation will provide us with vital information that will help prepare Australian children with disabilities for participation in community recreation and leisure activities. This research has the potential to enhance the participation opportunities and quality of life of children and their families in Australia.

**What are the possible risks and/or side effects?**
The participation in an interview poses no risk to you or Beitostolen Healthsports Centre. All data will be coded so as to preserve the identity and confidentiality of you and the organisation.

**What are the possible discomforts and/or inconveniences?**
Participation in the interview may take up to an hour of your time. This will not affect any part of your child’s stay and will not occur when there are specific information sessions, appointments or activities planned.

**Where is your information kept?**
All information is kept on a password secured computer in the private office of the investigator at BHC and UWA. This office is locked at all times when not in use and is only accessible by the researcher.

**What about my privacy?**
Participant confidentiality will be respected at all times. The results of this research may be published, however no identifying information shall be revealed. All data will be coded so as to preserve the identity and confidentiality of you and your child.

**Who has approved the study?**
The Princess Margaret Hospital Ethics committee has approved this research.

**Who to contact if you have any concerns about the organisation or running of the study?**
If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: 011 61 8 9340 8222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

**What to do next if you would like to take part in this research:**
If you would like to take part in this research study, please read and sign the consent form provided.

**Who to contact for more information about this study:**
If you would like any more information about this study, please do not hesitate to contact one contact one of the research team. They are very happy to answer your questions.

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**Claire Willis**
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THANK YOU FOR YOUR TIME
Appendix E5
Child Information Sheet (Norwegian)

INFORMASJON TIL BARN

Om studien:
En studie av en norsk rehabiliteringsmodell: Identifisere suksessfaktorer

Hvorfor gjør vi studien?
Din opphold ved Beitostølen Helseportsenter (BHSS) vil lære deg mange nye ferdigheter og aktiviteter som du kan delta i med familien. Du vil ha mye moro, få nye venner og lære nye ting.

Vi ønsker å lage et program som ligner på BHSS for barn i Australia. For å gjøre dette trenger vi deg til å fortelle oss de aller beste delene av oppholdet her, hva du vil være i stand til å gjøre når du går hjem, og noe som kunne ha gjort oppholdet enda bedre.

Hvem er forskerne?
Et team fra Australia og BHSS samarbeider om denne undersøkelsen. Teamet fra Australia er fra et barnesykehus som heter Princess Margaret Hospital (PMH), og et universitet som heter The University of Western Australia (UWA).

Hvem kan delta?
Barn som er på opphold på BHSS kan delta i denne studien.

Hva vil studien fortelle oss?
Studien vil fortelle oss de deler av programmet på BHSS som er viktigst for å hjelpe deg å delta i aktiviteter. Det vil også fortelle oss om vi kan lage et lignende program for barn i Australia.

Frivillig deltakelse:

Hva vil du bli bedt om å gjøre?

Du vil også fylle ut et skjema som heter Goal Attainment Scale, sammen med dine foreldre/din ledsager, for å hjelpe deg å nå dine mål. Dette er ikke en del av denne
studien, men en del av det som skjer på BHSS. Hvis det er ok for deg, vil vi gjerne se dine mål og høre hva du føler om dem på slutten av oppholdet.

**Er det sannsynlig at studien vil være en fordel for meg?**
Informasjonen du gir oss kan hjelpe instruktører å sørge for at du har et fint opphold.

**Vil informasjon fra studien være nyttig for andre mennesker i fremtiden?**
Informasjonen du gir oss vil hjelpe barn som deg i Australia til å delta i lignende aktiviteter med sine familier.

**Hva er de mulige risikoer?**
Når du snakker med oss utgjør det ingen risiko for deg. Å snakke med oss kan ta opp til en time. Dette vil ikke påvirke noen del av oppholdet, og vil ikke skje når det er planlagt aktiviteter eller spesielle avtaler.

**Hvor oppbevares din informasjon?**
All informasjon oppbevares på en passord-sikret datamaskin på forskerens private kontor på BHSS.

**Hva med personvernet?**
All informasjon du gir oss vil bli holdt privat. Vi vil publisere våre resultater i medisinske tidsskrifter, men din identitet vil ikke bli avslørt.

** Hvem har godkjent studien?**
De etiske komiteer på PMH og UWA har godkjent denne forskningen.

**Hvem kan jeg kontakte for mer informasjon:**
Hvis du ønsker mer informasjon om denne studien, ikke nøl med å kontakte en fra forskerteamet. De er veldig glad for å svare på dine spørsmål.

*Dr Jane Valentine*  
Chief Investigator  
Princess Margaret Hospital  
00 61 8 9340 8886  
Jane.Valentine@health.wa.gov.au

*Dr Siobhan Reid*  
Associate Investigator  
University of Western Australia  
00 61 8 6488 8781  
siobhan.reid@uwa.edu.au

*Dr Sonya Girdler*  
Associate Investigator  
Curtin University  
00 61 8 9266 3630  
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reijah@ous-hf.no

*Dr Catherine Elliott*  
Associate Investigator  
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Catherine.Elliott@health.wa.gov.au

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Associate Investigator  
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*Dr Reidun Jahnsen*  
Associate Investigator  
Beitostolen Healthsports Centre, Norway  
61 34 08 00  
reijah@ous-hf.no

Claire Willis
Hvem skal jeg kontakte om jeg har noen bekymringer om studien?
Hvis du har noen bekymringer eller klager angående denne studien, kan du kontakte Director of Medical Services på PMH (Telefonnummer: 011 61 8 9340 8222). Dine bekymringer vil meldes til Etikkutvalget som overvåker studien.

TAKK FOR OPPMERKSOMHETEN
Appendix E6

Child Information Sheet (English)

CHILD INFORMATION SHEET

A case study of a Norwegian rehabilitation model: Identifying elements of success

Why are we doing the study?
Your stay Beitostolen Healthsports Centre will teach you lots of new skills and activities that you can participate in with your family when you go home. You will have a lot of fun, make lots of new friends and learn lots of new things.

We want to create a program similar to Beitostolen Healthsports Centre for children in Australia. To do this, we need you to tell us the very best parts of your stay here, what you will be able to do once you go home, and anything that could have made your stay even better.

Who is carrying out the study?
There is a team from Australia and Beitostolen Healthsports Centre working together on this study. The team from Australia are from a children’s hospital called Princess Margaret Hospital, and a university called The University of Western Australia.

Who can take part?
Children who are staying at Beitostolen Healthsports Centre can take part in this study.

What will the study tell us?
The study will tell us the parts of the program at Beitostolen Healthsports Centre that are most important in helping you participate in activities. It will also tell us if we are able to create a similar program for children in Australia.

Do you have to take part?
No. You do not have to participate in this research. If you start the study, you are free to pull out at any time for any reason. You do not need to give a reason for pulling out. All your information will only been seen by us, we will not share it with other people. If we publish the results of this research your name or identity will not be revealed.

What will you be asked to do if you decide to take part in this study?
You will be asked to have an interview with one of the researchers from Australia towards the end of your stay. There will be someone in the room to help us understand Norwegian and English, in case you get stuck. The interview will take less than one hour. If you don’t want to answer one of the questions, you don’t have to. Any time you want to stop, we will.
You will also complete a form called the Canadian Occupational Performance Measure with your parent/carer as a part of your stay at Beitostolen Healthsports Centre. This will help you to make your goals. This is not a part of this study, but a part of what happens at Beitostolen Healthsports Centre. If it is ok with you, we would like to see your goals and if they change once you leave Beitostolen Healthsports Centre.

**Is there likely to be a benefit to me?**
The information you give us will be on record at Beitostolen Healthsports Centre and will be available to your instructors to help make your stay even better.

**Is there likely to be a benefit to other people in the future?**
The information you give us will help children like you in Australia participate in similar activities with their families.

**What are the possible risks and/or side effects?**
There is no risk to you or Beitostolen Healthsports Centre by talking to us. A code will be created to make sure everything you tell us stays with us.

**What are the possible discomforts and/or inconveniences?**
Talking to us may take up to an hour. This will not affect any part of your stay or be at the same time as any event or activity that your group has planned.

**Where is your information kept?**
All information you give us will be kept on a computer with a password in the private office of the researcher at BHC and UWA. This office is locked at all times when not in use, and only the researcher can get inside.

**What about my privacy?**
All the information you give us will be kept private. Eventually, we will publish our results in medical journals, but your identity will not be revealed.

**Who has approved the study?**
The Princess Margaret Hospital Ethics committee has approved this research.

**Who to contact for more information about this study:**
If you would like any more information about this study, please do not hesitate to contact one contact one of the research team. They are very happy to answer your questions.

*Dr Jane Valentine*
Chief Investigator
Princess Margaret Hospital
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Jane.Valentine@health.wa.gov.au

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Associate Investigator
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siobhan.reid@uwa.edu.au

*Dr Michael Rosenberg*
Associate Investigator
University of Western Australia
00 61 8 9380 2128
michael.rosenberg@uwa.edu.au
Who to contact if you have any concerns about the organisation or running of the study?
If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: 011 61 8 9340 8222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

THANK YOU FOR YOUR TIME
Appendix E7

Example recruitment and information letter for stakeholders

1st November 2013

Dear Parents,

Re: Expression of interest for involvement in community discussions

The Department of Paediatric Rehabilitation at Princess Margaret Hospital is inviting you to be a member of our Steering Group.

A steering group is a committee of people who guide and influence a project throughout the duration of the research. This Steering Group is being established to help us to develop a program that may help children with a disability to participate in activities in the community. Princess Margaret Hospital is working together with The University of Western Australia, Curtin University and Beitostolen Healthsports Centre (Norway) on this project.

The group will be made up of community members who have an interest in research directed at providing services to children with disabilities. To participate, we require you to be able to work well in a group environment, and to provide a link between our research group and the wider community. We have identified you as being able to give us important information that may be relevant to our research.

Appointment to the committee will be for two years, and meetings will be held no more than four times a year.

A more detailed summary of our research has been included with this letter to provide you with more information. If you would like to be involved, or have further questions, please contact:

Claire Willis
Department of Paediatric Rehabilitation, Princess Margaret Hospital
P: 0438 918 040
E: claire.willis@health.wa.gov.au

Following this letter, you may receive a phone call to formally invite you to participate in this Steering Group. Should you wish not to be contacted, please contact Claire Willis on the above details before Friday 8th November.
Thank you very much for your time and we look forward to receiving your response.

Kind regards,

Dr Anna Gubbay  
Paediatrician  
Department of Paediatric Rehabilitation, Princess Margaret Hospital

Claire Willis, PhD Candidate  
Accredited Exercise Physiologist  
Department of Paediatric Rehabilitation, Princess Margaret Hospital, School of Sport Science, Exercise and Health, The University of Western Australia
Appendix E8
Adult Consent Form

FORM OF CONSENT
(For Adult)

PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND SUBJECTS CAN WITHDRAW AT ANY TIME WITH NO IMPACT ON CURRENT OR FUTURE CARE.

I ........................................................................................................................................................................ have read

Given Names                                                             Surname

the information explaining the study entitled

A case study of a Norwegian rehabilitation model: Identifying elements of success

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction.

I understand I may withdraw from the study at any stage and withdrawal will not interfere with routine care.

I agree that research data gathered from the results of this study may be published, provided that names are not used.

Dated ..................................... day of ............................................................ 20 ..........

Signature .............................................................

I, ............................................................................................ have explained the above to the

(Investigator’s full name)

signatory who stated that he/she understood the same.

Signature ..................................................................................................
Appendix E9
Child Consent Form (Norwegian)

Samtykke til deltagelse
(For forelder/foresatt)

Deltakelse i denne forskningen er frivillig, og du står fritt til å trekke deg og barnet ditt fra studien når som helst. Dette vil ikke berøre deg eller barnet ditt sine rettigheter som bruker av BHSS.

Jeg ..................................................................................................................har lest
Navn til forelder/foresatt
informasjonen som forklarer studien

*En casestudie av en norsk rehabiliteringsmodell: Identifisere suksessfaktorer*

Jeg har lest og forstått informasjonen gitt til meg. Spørsmålene jeg har stilt er besvart.

Jeg samtykker til at mitt barn

...............................................................................................................................

Barnets navn
deltar i studien.

Jeg forstår at mitt barn kan trekke seg fra studien når som helst, og at dette ikke vil få noen konsekvenser.

Jeg er enig i at resultatene av denne studien kan bli publisert, forutsatt at navn ikke blir brukt.

Dato ..................................

Underskrift av barnet ....................................................................................

Underskrift av forelder/foresatt.................................................................
Jeg, ................................................................................. bekrer å ha gitt informasjon om
(Navn til prosjektansvarlig)

studien og at alle deltakerne forstår informasjonen.

Underskrift av prosjektansvarlig....................................................
Appendix E10

Child Consent Form (English)

FORM OF CONSENT
(For Parent/Guardian)

PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND SUBJECTS CAN WITHDRAW AT ANY TIME WITH NO IMPACT ON CURRENT OR FUTURE CARE.

I .................................................................................................................. have read

Given Names                                                             Surname

the information explaining the study entitled

**A case study of a Norwegian rehabilitation model: Identifying elements of success**

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction.

I agree to allow........................................................................................................

(full name of participant and relationship of participant to signatory)

to participate in the study.

I understand my child may withdraw from the study at any stage and withdrawal will not interfere with routine care.

I agree that research data gathered from the results of this study may be published, provided that names are not used.

Dated .................................. day of ............................................................ 20 .......

Child’s Signature ...........................................................................

(Where appropriate)

Parent or Guardian’s Signature ....................................................

I, .................................................................................................................. have explained the above to the

(Investigator’s full name)

signatories who stated that he/she understood the same.

Signature ...........................................................................................................