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An investigation of the role of social support on physical activity participation among adults with intellectual disability

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Abstract

Background: We know little about the lived experiences of people with intellectual disability and how these experiences relate to the social context in which health and wellbeing occur. In particular, little is understood about the role of social support in the lives of people with intellectual disability or the relationship between social support and health practices, the perspective used to understand physical activity in this thesis. This thesis attempts to make a contribution to this knowledge gap by investigating the relationship between a critically important aspect of the social environment, social support, and an equally important aspect of health and wellbeing, physical activity.

Objectives: The central research question of this thesis is: *What role does social support play in the health practices of people with intellectual disability, specifically in relation to their participation in physical activity?*. In answering this question, the thesis had the following aims:

- To identify good practice when conducting inclusive qualitative research with people with intellectual disability;
- To develop an understanding of social support for people with intellectual disability;
- To develop an understanding of the role social support plays in health practices, such as physical activity, for people with intellectual disability

Design: The research presented in this thesis used a methodology that places people with intellectual disability at the forefront of their own experiences. The methodological approach is firmly based on the key principles of inclusive research, which meaningfully engages participants, is participant focused, and seeks the active engagement of people with intellectual disability in all research processes. To inform this approach, a systematic mapping of qualitative research methods used with people with intellectual disability was conducted to identify good practice when conducting research which is inclusive of people with intellectual disability. Through this review, a ‘blueprint’ of inclusive research practices that can be used by researchers to be inclusive of people with intellectual disability as *participants* was developed and guided the research. In-depth interviews, photovoice and participant observation were used to collect data from seven participants with intellectual disability.

Results: Findings suggest participants experience social support in complex and diverse ways. Participants experienced the complex nature of informal and formal support and this support occurred along a continuum. Related to this finding, participants had differing understandings of relationships, particularly friendships. Participants also experienced the impact of fluid relationships and a lack of social stability in their social network resulting in changes to the support available to them. The results of the thesis were used to refine and develop an understanding of social support for people with intellectual disability.

The thesis also found the relationship between physical activity and social support was multidirectional (i.e., social support facilitates physical activity and physical activity enables social support). When looking towards the support participants used to be active, companionship support was key as was the practical support provided through informal and formal supports.

Conclusion: The research presented in this thesis aimed to understand the role of social support in physical activity participation. In doing so, it also developed an understanding of social support for people with intellectual disability and developed a blueprint of inclusive research practices to guide qualitative research investigating these areas. The blueprint seeks to support researchers to actively include and engage people with intellectual disability in qualitative research. Finally, the thesis proposes an alternative approach to developing health promotion initiatives for people with intellectual disability, one that embodies the key principles of inclusive research to meet the needs and consider the context of their experiences to produce sustained changes in behaviour.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, financial support and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my higher degree by research candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications included in this thesis

No publications included.

Submitted manuscripts included in this thesis

Brooker, K., Mutch, A., & van Dooren, K. (submitted). Conducting research that actively and genuinely engages people with intellectual disability: a systematic mapping of the literature. *Journal of Applied Research in Intellectual Disability*.

This manuscript is incorporated in Chapter 4.

Contributor	**Statement of contribution**
Brooker, K. (Candidate)	Conception and design (70%) Analysis and interpretation (70%) Drafting and production (70%)
Mutch, A. (Associate advisor)	Conception and design (15%) Analysis and interpretation (15%) Drafting and production (15%)
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Poster presentations

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Contributions by others to the thesis

Dr Kate van Dooren and Dr Allyson Mutch (PhD advisors) provided extensive input into the concept and content of this thesis. They reviewed and provided considerable feedback at all stages of the thesis.

Statement of parts of the thesis submitted to qualify for the award of another degree

No works submitted towards another degree have been included in this thesis.

Research involving human or animal subjects

Ethical approval was received from the Behavioural and Social Sciences Ethical Review Committee at UQ, approval number 2012000460 (Appendix A).

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Keywords

intellectual disability, physical activity, social support

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List of abbreviations used in the thesis

AIHW	Australian Institute of Health and Welfare
IQ	Intelligence Quotient
OCD	Obsessive Compulsory Disorder
QCIDD	Queensland Centre for Intellectual and Developmental Disability
WHO	World Health Organization

Chapter 1 Introduction

Arguably, we know little about the lived experiences of people with intellectual disability. Certainly it has been well-demonstrated that, as a group, individuals with intellectual disability experience social exclusion, discrimination during activities such as education and employment (Kozma, Mansell, & Beadle-Brown, 2009; Stancliffe, 2012), and substantial health inequities across physical and mental health (Krahn & Fox, 2014; Robertson, Hatton, Baines, & Emerson, 2015). However, as important as this knowledge has been to improving outcomes for individuals (such as through improved medical intervention (Robertson et al., 2015)), the academic literature has largely overlooked lived experiences as viewed by individuals themselves, particularly as these experiences relate to the social context in which health and wellbeing occur. Although less clinically focussed, such an exploration is vitally important given the well-established associations between social experiences and physical and mental health (Haskell et al., 2007; McTavish, 2011).

This thesis attempts to make a contribution to this knowledge gap, by investigating the relationship between a critically important aspect of the social environment, social support, and an equally important aspect of health and wellbeing, physical activity. Specifically, the research presented in this thesis aims to improve understanding of the role social support plays on physical activity, using a methodology that places people with intellectual disability at the forefront of their own experiences. In particular, the methodological approach is firmly based on the key principles of inclusive research, which meaningfully engages participants, is participant focused, and seeks the active engagement of people with intellectual disability in all research processes (Bigby, Frawley, & Ramcharan, 2014; Walmsley & Johnson, 2003).

This chapter lays the groundwork for the research presented in this thesis, including the literature reviews. It provides definitions for intellection disability, and explains decisions taken about language and terminology use. It explains the research issue in brief, presents the research question and aims, and provides a brief outline of the thesis structure.

1.1 Defining intellectual disability

Disability, and in turn intellectual disability, can be variously understood depending on beliefs about the origin of disability. Intellectual disability is most commonly conceptualised using two distinct approaches: the medical model and the social model.

Each model will be discussed in detail below with a focus on the latter, which guides the work presented in this thesis.

The medical model arguably takes a deficiency approach to disability, which it views as located within the individual. Accordingly, an individual with disability is seen as a ‘problem’ to be fixed (Oliver, 2009). An individual who does not verbally communicate and is unable to understand instructions therefore needs to learn these skills. Widely accepted international definitions of intellectual disability from the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) and the American Association on Intellectual and Developmental Disabilities (Schalock et al., 2010) draw on the medical model to focus on individual deficits in intellectual functioning and adaptive behaviour (e.g., activities of daily living, social skills, personal care, communication), which commence in the developmental period. ‘Level’ of intellectual disability is important for these definitions, which rely on categorisation: individuals are classified as having mild, moderate or severe disability, based on a combination of IQ testing and assessment of their adaptive functioning (American Psychiatric Association, 2013). Despite the criticism from disability advocates, it is worth drawing attention to the utility of the medical model for people with intellectual disability. A medical model perspective aims to find the cause of intellectual disability, which for some, could be useful to understand and support their needs, particularly when considering health-related issues (Cocks, 1998). This perspective, however, can be limiting in that it considers neither external factors that inevitably affect individuals, such as discrimination, nor external responses that could improve experiences, such as enhanced communication from health professionals working to support individual need (Cocks, 1998).

In contrast to the medical model, the social model sees disability as a collective experience created by society as a form of oppression; in doing so, the social model acknowledges that impairment is distinct from disability (Oliver, 2009). The social model sees impairment as a personal attribute; it recognises disability arises from interactions between individual impairment and environmental and socio-political barriers (Oliver, 1996). These barriers include, but are not limited to, physical accessibility to buildings and transport options, lack of accessible signage and information, and attitudes that result in discrimination from employment, education or the community. The social model of disability originated from the disability rights movement in the 1970s (Oliver, 1996) and has been heavily developed and influenced by people with physical disability. Notably, the model has seen minimal input from people with intellectual disability (Bigby & Frawley, 2010). Chappell (2000) argues the absence of this group may be due to the emphasis the social model of disability places on impairment located within the physical body. Furthermore, the setting in which discussions and debates occur about the social model are largely exclusionary of people with cognitive impairment, including the academic sphere where material is discussed in theoretical terms, debate is heavily based on text, and entry to the field is through higher education (Chappell, 2000). However, the social model of disability remains useful for people with intellectual disability since it demands understanding of the wider context of people's lives and their disabling experiences.

1.2 Terminology adopted by this thesis

This thesis uses the term 'intellectual disability' to reflect Australian terminology (Wen, 1997). 'People first' language is used to acknowledge the person comes before the disability, in recognition of the documented preferences of many people with intellectual disability (People with Disability Australia, 2016). Further, the research, including the vast majority of literature reviewed, relates to those who, according to medical classification, would be considered to be experiencing 'mild' intellectual disability. However, the participant's in this doctoral research have not been categorised using a medical classification, rather, participant's reflect individuals who can participate and contribute to their family and community; have important relationships in their life; may be employed, live and travel independently or with some support; able to handle money and plan their daily life or with some support; who may marry and have children; and learn to read and write (Australian Institute of Health and Welfare, 2008). This understanding acknowledges the need for support may vary across an individual's life course, for example, during key transition points such as moving from school to the workforce. Importantly, by grounding this research in the social model of disability the thesis also acknowledges that individual capacity to make autonomous decisions may be limited to factors beyond impairment. For example, due to the involvement of support people (i.e., family, friends, paid support staff) some individuals may have limited opportunities to make their own choices, ranging from which activity they attend at their day activity organisation, to the people they live with or choose to support them.

Throughout this doctoral research, the aim has been to develop a respectful and meaningful understanding of the experiences of individuals with intellectual disability, and in particular the experiences of the participants of the research. In doing so, the needs and experiences of participants were directive to the research process. Participants were seen as experts in their experiences who could participate and contribute to the research fully (with support when desired). Consistent with the social model of disability, the research process aimed to capture the wider context of individual's lives particularly regarding their physical activity and social support experiences.

Throughout this thesis and when reviewing the literature, I have been cognisant that the power of language cannot be underestimated; language may convey respect and contribute to building trusting working relationships. Although it must be acknowledged that ideally, individuals should be viewed as just that, individuals, this research is situated as a piece of doctoral work that aims to contribute to academic understanding of people with intellectual disability. Therefore, language has been adapted to suit an academic context; however, it is worth noting here, that throughout interactions with participants, disability was rarely explicitly discussed, as experiences for them extended far beyond living with intellectual disability. Consequently, terminology used throughout this thesis alternates to describe individuals who, as participants, shared their experiences versus the population group – people with intellectual disability – who are discussed and described by the literature.

1.3 Research issue

Although our understanding is continuously improving, arguably, relatively little is understood about how to effectively promote sustainable and autonomous behaviours that enhance health and wellbeing among adults with intellectual disability (Naaldenberg, Kuijken, van Dooren, & Van Schrojenstein Lantman-de Valk, 2013). Perhaps given the inevitable reliance on medical model approaches to disability in public health research, even less is understood about the role of social context when considering health and wellbeing for this group. Consequently, a dearth of evidence – qualitative and quantitative – exists related to how social support is associated with health and health behaviours for people with intellectual disability (Lunsky, 2006; McConkey, 2005).

When reflecting on the health promotion literature for people with intellectual disability, several limitations to current approaches exist. Namely, the oversimplification of the complex set of practices and context that surround people with intellectual disability influencing their ability to engage in health promoting behaviours. Due to these limitations, this thesis takes a health practices approach to understanding health behaviours. A health practices approach acknowledges that a health behaviour does not occur in isolation, rather, a set of practices form the action related to the health behaviour (Mielewczyk & Willig, 2007). It places emphasis on the broader social context in which health practices occur (Delormier, Frohlich, & Potvin, 2009). A health practices approach is particularly relevant for people with intellectual disability given the potential for a diverse range of experiences relating to social context including social support, the experience of receiving and potentially relying on disability support and the experience of disablement (e.g., inaccessible physical activity options).

As social support forms a key component of the social context, social support is explored in detail in this thesis. Consistent with a health practices perspective, Williams, Barclay, and Schmied (2004) advocate for an understanding of social support based on the context of the population group under investigation. This thesis aims to develop an understanding of social support and in doing so, address a clear knowledge gap that exists in the extant literature, which offers little clarity regarding a definition appropriate to and inclusive of people with intellectual disability (Lunsky, 2006). The thesis also aims to explore the role of social support in physical activity participation; social support is well known to be beneficial to health (Berkman, Glass, Brissette, & Seeman, 2000; McTavish, 2011) and to play a role in health behaviours (Reblin & Uchino, 2008). In particular, this role has also been highlighted for people with intellectual disability; people report that having someone to be active with is an enabler of physical activity (Frey, Buchanan, & Sandt, 2005; Taliaferro & Hammond, 2016; Temple, 2009).

Selecting appropriate methods to conduct this research was critical for including this population group in a meaningful way and it was decided that embracing an inclusive research methodology would best address the research question, as it seeks the active engagement of people with intellectual disability (Bigby et al., 2014; Walmsley & Johnson, 2003). However, little guidance was found in the literature for researchers aiming to inclusively engage with individuals as research participants. Therefore, the thesis sought to develop a guide to conducting good practice qualitative research with people with intellectual disability that embodies the key principles of inclusive research.

1.4 Research question

The central research question of this thesis is: *What role does social support play in the health practices of people with intellectual disability, specifically in relation to their participation in physical activity*? In addressing this question, the following aims will be used to direct both the method and focus of this inquiry:

- To identify good practice when conducting inclusive qualitative research with people with intellectual disability;

- To develop an understanding of social support for people with intellectual disability;
- To develop an understanding of the role social support plays in health practices, such as physical activity, for people with intellectual disability.

1.5 Contribution of the research

The findings arising out of this thesis will include a critical appraisal of relevant literature related to content and methodology, as well as analysis of data collected using an inclusive approach and practices. These findings will represent a well-considered approach to conducting research with people with intellectual disability that aligns research values with the social model of disability, in that the research has considered the lived experiences of individuals and moves understanding beyond that of disablement. Importantly, the reflections on the approach used are in many ways as valuable as the findings presented.

In terms of the inclusive approach adopted by this research, reflections will contribute to furthering academic discussion about the need to build a research agenda that actively supports the inclusion and participation of people with intellectual disability in research and knowledge production about themselves as both participants of research and as researchers. In reflecting on good inclusive practices and the challenges associated with adopting them, this thesis attempts to clarify what constitutes inclusive research, and to progress understanding of the resources and skills needed to embody such an approach. Through this clarification it is hoped that we, as researchers, can move beyond speculating what inclusive research may look like to focus on identifying the steps needed to overcome the challenges of conducting inclusive public health research. Only then can expectations of inclusivity be fully embraced and ultimately met.

Additionally, this thesis will contribute to understandings of social support as experienced by people with intellectual disability. The social model of disability and inclusive research guiding this research demand the importance of contextualising experiences against the backdrop of individuals’ lives. It is insufficient to consider health-related issues experienced by people with intellectual disability, including physical activity, in isolation of their social lives. Instead, this thesis attempts to better understand the role that social support plays in individuals’ engagement in health practices such as physical activity. Such an understanding will inform future health promotion efforts for people with intellectual disability across research, policy and practice. This thesis will contribute to future research efforts to explore sustainable health promotion interventions; findings can be used to inform policies that support and promote health practices and inform the practice of those supporting people with intellectual disability.

1.6 Thesis structure

Chapter 2 describes social support, and in doing so, provides a foundational exploration of this concept that serves as a platform from which health practices may be understood. As such, this chapter provides critical information to address the research question of this thesis. The chapter reviews the relevant literature to describe study findings and to identify current knowledge gaps as well as the key elements of social support for people with intellectual disability (as it is currently understood). The thesis continues to refine these key elements throughout the processes of data analysis and interpretation in later chapters. Finally, this chapter introduces proposed mechanisms through which social support influences health, which are further explored in the next chapter.

Chapter 3 examines physical activity for people with intellectual disability using a health practices lens. A brief review of physical activity research involving people with intellectual disability is presented. This review critically reflects on the gaps in this literature to inform the selection of health practices as an alternative approach to understanding physical activity. It is noted that a health practices approach is consistent with both the social model of disability and an inclusive research methodology.

Chapter 4 presents a discussion of inclusive research, which is the methodological approach used in this thesis. The chapter starts with a discussion of the history of inclusive research and different inclusive approaches used by researchers to date. It highlights how the principles of inclusive research can be applied to the way researchers engage people with intellectual disability as participants in research. This approach is the focus of the review of qualitative research that is then presented. This review has been submitted for publication to a peer review journal. The review aims to identify inclusive research practices that reflect the key principles inclusive research. Arising out of the findings of the review is a blueprint of inclusive research practices for qualitative research that informs the study design used throughout the remainder of the thesis. The implementation of these research practices is more tangibly discussed in Chapter 5, which outlines the specific methods used in this thesis to answer the research question.

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Chapters 6 and 7 present the results of the study described in the methods chapter. Chapter 6 presents participant vignettes that aim to contextualise participants’ lived experiences, as they relate to physical activity and social support. Chapter 7 presents the key themes arising out of the data analysis, which attempted to understand how participants use social support to engage in physical activity.

Chapter 8 presents and integrates the findings of the two results chapters and reflects on how this addresses the thesis’s research question and aims. This chapter considers how the study findings can be applied to refine and expand our understandings of social support for people with intellectual disability. The findings are also considered in terms of their potential contributions to health promotion efforts for people with intellectual disability and progressing an inclusive research agenda within public health. The research approach taken in this thesis is reflected on and possible ways forward for future research is identified. The strengths and limitations of the study are discussed.

Chapter 2 Understanding social support for people with intellectual disability

This thesis takes a health practices perspective to examine the relationships between social support and physical activity. Health practices are grounded within social practice theory, and represent an approach to considering health and health-related behaviours that focuses on understanding the social and individual context (e.g., social support) surrounding the practice (e.g., physical activity) (Mielewczyk & Willig, 2007). Therefore, to understand health practices, it is pertinent to first provide a foundational understanding of social support for people with intellectual disability. This chapter reviews the social support literature and considers how it relates to people with intellectual disability. It describes key findings and identifies current knowledge gaps.

The aim of this chapter is to solidify understanding of social support as it relates to people with intellectual disability. Two questions, *What function do social relationships play in their lives of people with intellectual disability?* and *What type of support do paid support staff, family and friends offer?*, will be explored. Key elements of social support will be presented and refined throughout the chapter. As will be demonstrated, substantial gaps exist in the conceptualisation of social support for people with intellectual disability, and so it is appropriate to continue to refine and expand on these key elements as the thesis progresses. A list of key elements will be presented at the conclusion of this chapter, and this list will be refined throughout the rest of the thesis.

This chapter is presented in four sections. The first section explores the health benefits associated with social support, to provide a rationale for focusing on social support as a critical concept. Section two examines key concepts relevant to social support. Section three presents a brief review of studies that have investigated how people with intellectual disability understand and experience social support and identifies gaps in the current literature. The final section describes proposed mechanisms through which social support influences health, laying the groundwork for Chapter 3, which describes, in detail, physical activity as a health practice.

2.1 Health benefits related to social support

An extensive body of literature developed over the past four decades has identified a strong and positive association between social support and a broad range of health outcomes (Berkman et al., 2000; McTavish, 2011). Researchers have also identified the positive relationship between social support and health promoting practices such as physical activity (Reblin & Uchino, 2008). Conversely, the absence of social support or negative social support is associated with poor health (McTavish, 2011; Reblin & Uchino, 2008). Most recently, researchers have found the relationship between social support and health can vary across an individual's life course due to different life experiences and needs at different points in time (Hakulinen et al., 2016; Umberson, Crosnoe, & Reczek, 2010).

The experience of high quality social support has consistently been associated with decreased premature mortality (Holt-Lunstad, Smith, & Layton, 2010; Reblin & Uchino, 2008; Uchino, 2006). A meta-analysis conducted by Holt-Lunstad et al. (2010) found participants who had stronger social relationships had a reduced risk of premature morbidity and mortality. Specifically, social support has been linked to reduced premature mortality due to cardiovascular disease and cancer (Holt-Lunstad et al., 2010) while the absence of social support, particularly emotional support, has been linked to increased rates of prostate cancer mortality (Jan et al., 2016).

In addition to reducing premature mortality rates, social support is associated with improved physical and mental health outcomes (McTavish, 2011; Reblin & Uchino, 2008). A large body of work has focused on cardiovascular outcomes and disease; participants with high levels of support were less likely to be readmitted to hospital after a cardiovascular event than those with lower levels of social support (Reblin & Uchino, 2008). Social support has also been found to be beneficial to the management of other diseases such as diabetes, hypertension and arthritis where people with high levels of support self-report better outcomes (Reblin & Uchino, 2008). In terms of mental health, low levels of social support have repeatedly been found to be related to an increased risk of depression which in turn can also negatively impact physical health (Grav, Hellzen, Romild, & Stordal, 2012; Turner & Brown, 2010).

2.2 Defining social support

It is important to understand the different concepts and terminology that are used to explore the role of social support to inform the health practices discussion in the next chapter. This section, while descriptive, also provides important grounding for subsequent discussion of the limitations of current definitions of and approaches to social support and how they relate to people with intellectual disability.

For reasons described throughout this section, researchers have demonstrated limited consensus on a universal definition of social support (Hupcey, 1998; Williams et al., 2004). Consequently, a range of definitions exist. Some definitions stem from broad understandings that social support arises from the resources provided in social relationships and focus on individual level supports and relationships (e.g., Berkman, 1995; Cohen & Syme, 1985). Other definitions encompass a community level approach where an individual feels cared for, loved and valued within their community and social networks (e.g., Cobb, 1976; Sarason, 1974). Social support has also been understood as a social determinant of health. Wilkinson and Marmot (2003) describe social support as "operating on the levels both of the individual and of society" (p. 22) and acknowledge social isolation, social exclusion and social cohesion as important related concepts.

These different definitions inform the approaches taken by researchers aiming to understand experiences of social support, including interventions to change improve experiences. For example, Campbell and Gilmore (2014) used a broad definition to evaluate a social support intervention aiming to improve mental health and wellbeing among adolescents with intellectual disability by improving their interpersonal relationship skills. Social support was defined as "emotional and physical comfort provided to individuals by other people" (Campbell & Gilmore, 2014, pp. 22-23). This definition was consistent with the individual level approach of the intervention. Taking another approach, Lunsky and Neely (2002) acknowledged the importance of understanding community in their descriptive research investigating the sources of social support for people with intellectual disability. Their understanding of social support included consideration of social integration, the social environment, and social networks including connections to organised groups, places and people (i.e., service organisations, workplaces, extended family members).

Function and structure have been identified as important to understanding social support (Heaney & Israel, 2008). Functional social support research investigates the benefits that are perceived to be transferred to and from individuals in the relationship. Three well-researched functions are *emotional support*, *practical support* and *informational support* (Heaney & Israel, 2008; Stansfeld, 2005). Emotional support is most clearly illustrated when people express encouragement and trust in an individual (Heaney & Israel, 2008; Stansfeld, 2005). It can include relationships that provide companionship, encouragement, empathy, a sense of being believed in and a sense of belonging (Williams et al., 2004). Individuals may also experience or provide practical support, including financial support (Heaney & Israel, 2008; Stansfeld, 2005). Informational support refers to the provision of information, guidance or advice to an individual (Heaney & Israel, 2008; Stansfeld, 2005).

Another concept used to investigate social support relates to structure. A structural approach reflects the composition of the social relationships, or, the *social network* of an individual. Social networks refer to the social structure of an individual’s social interactions and relationships (Heaney & Israel, 2008). An individual’s social network is centred around the individual and consists of their interactions and relationships (i.e., social ties). These social ties may provide social support to the individual and usually involve family, friends and acquaintances (Israel, 1982). Social network members can be interconnected with other members of the social network (e.g., when two individuals have mutual friends). It is important to note that in social support research, researchers generally make assumptions about ubiquitous understandings of friendship and avoid formally defining what friend or friendships mean to the individuals involved. Berndt and McCandless (2014) explicitly acknowledge the difficulty of defining these terms, which they suggest generally reflect a mutual relationship where individuals know and like each other and have shared interests and experiences.

The relationships that exist within a social network can be classified as *bonding*, *bridging* and *linking relationships*. Bonding relationships refer to the close relationships of an individual (e.g., family and friends) who are part of the same social network and are alike (Kim, Subramanian, & Kawachi, 2006). These relationships often provide emotional, practical and informational support (Domínguez & Arford, 2010). Bridging relationships reflect acquaintances or relationships among individuals who are dissimilar but who are at a similar hierarchical level (Kim et al., 2006). Bridging relationships allow new information to be cycled through social networks (Hawkins & Maurer, 2010). Linking extends on this notion, reflecting the access an individual has to opportunities outside of their normal social network to people of higher hierarchy and power (Szreter & Woolcock, 2004). These relationships have similar benefits to bridging relationships since they allow new information to be cycled through social networks.

Related to bridging and linking relationships is what Granovetter (1973) describes as *weak ties*. Weak ties refer to the acquaintances of a social network; an individual is less involved with weak ties when compared to strong ties (i.e., family, friends) (Granovetter, 1983). Weak ties can connect network members to different social groups and settings, potentially leading to a broader range of experiences and information on which the individual may draw (Granovetter, 1983; Kavanaugh, Reese, Carroll, & Rosson, 2005). A social network with few weak ties “will be fragmented and incoherent” since transfer of ideas and information and sharing of experiences is slow due to the fewer number of people interacting (Granovetter, 1983, p. 202).

Key to discussion of social support and the relationships within a social network, particularly those involving people with intellectual disability, is the clear distinction between formal and informal support. Social relationships can provide different functions of social support and the relationships or ties providing this support can come from a range of different sources (e.g., family, friends and/or neighbours). Informal support is considered to be part of everyday life and is defined as support “provided by individuals who have primary relationships with the recipient” (Lipman & Longino, 1982, p. 142). Informal support is based on bonding relationships rather than payment. In contrast, formal support is understood that which “operates within the context of the bureaucratic structure” (Lipman & Longino, 1982, p. 142) and is often task focused, requiring specific training and the application of professional knowledge and skills. Formal support is also often associated with paid support (Lipman & Longino, 1982).

Other important concepts need to be considered when understanding social support. In a review aiming to develop a definition of social support, Williams et al. (2004) acknowledged *time* as important, because social support can arise from social relationships that provide short-term or ongoing support (Williams et al., 2004). In this case, the researchers’ understanding of social support is so detailed that the definition is over one page long, with key elements including specification of the way people use social support, and understanding that the meaning and importance of social support to an individual may change across an individual’s life course (Cohen & Syme, 1985). Other researchers have made efforts to consider the *reciprocity* of relationships (Callus, 2017; Fulford & Cobigo, 2016; Lafferty, McConkey, & Taggart, 2013). Reciprocity refers to when social support is both given and received in a relationship (Callus, 2017). In one of the few studies to seek the views of people with intellectual disability involved in romantic relationships, Lafferty et al. (2013) found couples valued mutual support and reciprocation as key to a good relationship.

Finally, it has been stressed by some researchers that *negative support* can arise from relationships (Heaney & Israel, 2008). The experience of negative support is an increasingly reported barrier among people with intellectual disability. For example, Taliaferro and Hammond (2016) found the overprotective and risk adverse behaviours of support people acted as a negative support for people with intellectual disability. Support people discouraged the people they supported from participating in a physical activity if they felt there was a risk to health or safety. Instead, support people preferred to choose safe activities, even if they were not the preferred activity of the individual (Taliaferro & Hammond, 2016).

As has been demonstrated in the description of concepts and functions above, social support is complex and multidimensional and no single definition exists (Heaney & Israel, 2008; Hupcey, 1998). However, some researchers have attempted to bring together important notions of social support in an attempt to clarify understanding (Hupcey, 1998; Williams et al., 2004). Hupcey (1998) grouped definitions into five categories according to their focus on (1) the function of the support provided (e.g., emotional support); (2) the recipient’s perceptions of support (e.g., whether they thought the support was helpful); (3) the intentions or behaviours of the provider of support (e.g., the provider of support perceives a need); (4) reciprocal support (e.g., when social support is both given and received by an individual); and (5) social networks (e.g., when social support is accessed through individuals, groups or community). As discussed above, Williams et al. (2004) developed a comprehensive understanding of social support; their understanding reflects the elements of social support discussed in this section. Williams et al. (2004) also highlighted that social support is used and understood differently by different groups of people and as such, needs to be specifically defined for the population group of interest using an inductive approach. Currently, most of the common definitions of social support are based on deductive research (Williams et al., 2004). This is problematic because the definitions do not consider the context in which the population experiences social support. However, these definitions have been useful as they have provided a starting point for researchers and, due to their simple nature, are easy to utilise in research. Additionally, the majority of definitions have overlooked negative aspects of social support, focusing on positive interactions (Hupcey, 1998). A seminal paper in physical activity research by Frey et al. (2005), examining the physical activity participation of people with intellectual disability, found participants experienced both positive and negative social support. Participants described experiences of positive social support that promoted their own physical activity (e.g., prompts to exercise) as well as negative social support that restricted their ability to be active (e.g., support people restricted access to physical activity opportunities due to concerns over safety).

In sum, there exists great variation in the focus researchers take when defining social support (e.g., individual *versus* community level) as well as the elements they consider to be important when describing social support (e.g., time, reciprocity, positive versus negative support). Drawing on this vast literature of various definitions and concepts it is possible to identify key issues that should be identified when exploring the role of social support for people with intellectual disability. These include the five elements of social support identified by Hupcey (1998), elements that are specific to the population group of interest, and both positive and negative aspects of social support.

2.3 Intellectual disability and social support literature

The following section builds on the above discussion of the different elements of social support, to explore the literature on the role of social support for people with intellectual disability. An extensive body of research has considered social support; however, more limited work relates to people with intellectual disability. Traditionally, and consistent with other areas of intellectual disability research, this area has been heavily dominated by research that seeks the views and perspectives of proxy respondents. Since the early 2000s, researchers have shifted towards gathering data from people with intellectual disability. This shift was influenced by the social model of disability and the inclusive research movement; both advocated for the inclusion of people with intellectual disability in research about them (for further discussion on the social model of disability see Chapter 1 and inclusive research see Chapter 4). Research has demonstrated that people with intellectual disability are reliable reporters about the social support they experience and as such should be engaged in research as active participants (Lunsky & Benson, 1997).

The literature reviewed here, and throughout this thesis, focuses on research that presents data collected from people with intellectual disability themselves as opposed to proxy respondents. However, it is acknowledged that at times it may be useful to draw on proxy respondents or to engage with literature that has sought the experiences of support people to further inform the views of people with intellectual disability. Where research involving support people is discussed, this is clearly indicated. The section below will briefly review research that has aimed to understand social support, explore the role of social support and improve social support for people with intellectual disability.

Understanding social support for people with intellectual disability

As already indicated in the previous section, understandings of social support should be developed for each population group based on the context of their experiences. This is particularly relevant in the current context because researchers often draw on definitions of social support developed with reference to other populations without giving consideration to how they may be different for people with intellectual disability (see for example, Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011). This may be problematic as individuals with intellectual disability may not have had opportunities to develop and refine skills needed to maintain social relationships, particularly if an individual has experienced segregated settings (e.g., sheltered workshops, day service activities specifically for people with disability) (Lunsky, 2006). Some individuals may receive much of their support from formal networks (e.g., through the provision of disability-related support) which, in turn, may restrict their opportunity to develop and maintain relationships. Individuals may experience reduced autonomy, reduced opportunity to diversify their social networks and environmental restrictions (Lunsky, 2006). In response to experiences of social support, people with intellectual disability may have distinct understandings of what social support means to them, including the function of social relationships in their lives.

Only a small number of studies have taken a step towards clarifying understandings of social support for people with intellectual disability (Knox & Parmenter, 1993; Lunsky, 2006). Knox and Parmenter (1993) aimed to understand the mechanisms of social support for individuals with intellectual disability in a workplace setting. Nine participants with ‘mild’ intellectual disability participated in participant observations and discussions in their workplaces and homes over an 18-month period (Knox & Parmenter, 1993). Within the study, social support was defined as a “resource flowing through a network tie considered helpful by the individual him or herself” (Knox & Parmenter, 1993, p. 7). The researchers identified three forms of social support arising from their data: companionship support (sharing the company of others), emotional support (regarding wellbeing, reassurance and advice) and instrumental support (direct practical help). The researchers also reported that in terms of social network members, parents and service organisations were the main providers of support and that often support came from segregated as opposed to integrated settings (i.e., support came from connections at a supported worked place as opposed to friends). The researchers also postulated some of the friendships participants described were more akin to acquaintances or unreciprocated friendships. From these findings, it can be seen people with intellectual disability experience similar functions of social support (i.e., emotional support, practical support) as often identified by other population groups but that they also valued having a companion and someone with whom they could spend time.

Lunsky (2006) also attempted to clarify social support for people with intellectual disability, through understanding of the influences of social support for people with intellectual disability. She developed a model, based on a review of social support literature, whereby social support is a product of social relationships. The key element of the model is that social support can be influenced at three levels: individual, community (i.e., the social environment) and relationship levels. The individual level encompasses physical attributes (e.g., the way a person looks, the way they are perceived by others), relationships skills, an individual's desire and motivation to make and maintain relationships and the cognitive ability of the individual. Community encompasses similar characteristics: the physical accessibility of the environment, the skills of the community to engage in providing and reciprocating support, the motivation and attitude of the community and environment and the cognitive ability of individuals within the environment (e.g., in a segregated setting) (Lunsky, 2006). The final level relates to interpersonal relationships and considers the structural and functional aspects of a relationship, whether it is positive or negative and whether it is perceived or received (Lunsky, 2006). Consistent with a social model of disability perspective, this multi-level understanding acknowledges that individual and external factors have an influence on relationships and social support. It also incorporates and acknowledges the concepts around relationships such as the structure and function of relationships and if the relationship provides positive or negative support. This is consistent with the elements identified above by Hupcey (1998) and Williams et al. (2004).

The role of social support in the lives of people with intellectual disability: what we know

Turning now to the role of social support in the lives of people with intellectual disability, the following section will briefly review research that has investigated social support for people with intellectual disability. Consistent with the focus on individual level relationships and social networks in other population groups, this research has focused on relationships and social networks. Literature is presented accordingly below.

A growing body of research within intellectual disability and social support literatures concerns personal relationships. Although family members and paid support staff have significant roles in individuals' lives, little research has explored these relationships (Widmer, Kempf-Constantin, Robert-Tissot, Lanzi, & Carminati, 2008). Instead, research has tended to focus on how people with intellectual disability perceive friendships and make friends, with some more limited investigation of intimate relationships (Fulford & Cobigo, 2016).

The experience of personal relationships and, in particular, friendships for people with intellectual disability are varied but share some common experiences consistent with the broader social support literature (Bane et al., 2012; Healy, McGuire, Evans, & Carley, 2009). People with intellectual disability have reported the importance of having good relationships with family, friends and paid support staff; however, they have also reported feelings of being treated like children, particularly in response to their romantic relationships (Bane et al., 2012). Regarding friendships, people with intellectual disability have reported enjoying the companionship of friends (Fulford & Cobigo, 2016; Knox & Hickson, 2001; Lafferty et al., 2013); spending time together and sharing in activities with friends (Fulford & Cobigo, 2016; Knox & Hickson, 2001; Pottie & Sumarah, 2004); and being in trusting reciprocal relationships (Knox & Hickson, 2001; Salmon, 2013). Individuals have also identified the importance of shared history and experience of stigma among their friends who also have intellectual disability (Knox & Hickson, 2001; Salmon, 2013). Additionally, Fulford and Cobigo (2016) found people with intellectual disability preferred to be friends with people with similar support needs to themselves.

As could be expected given their diversity of backgrounds and experiences, people with intellectual disability are likely to have personal and nuanced understandings of how friendships are formed and maintained. Individuals are more likely to develop friendships with other people with intellectual disability rather than people without intellectual disability (Emerson & McVilly, 2004). Furthermore, researchers have identified that some do not hold clear boundaries when it comes to friendships. For example, Jahoda and Pownall (2014) compared the social networks of adolescents with and without intellectual disability and found the former identified what the researchers would have described as acquaintances as close and important relationships. Other researchers (Clegg & Standen, 1991; Lippold & Burns, 2009; Lunsky, 2006) have identified similar notions of ‘misinterpreted’ friendship. Some people with intellectual disability may interpret friendly gestures or frequent contact with an individual as friendship when the relationship may be superficial and more similar to what others would call an acquaintance or even a formal support. It is important to note that while the individual may perceive friendship, often these relationships are not reciprocated, for a variety of reasons, not least the importance of boundaries for paid support staff (Clegg & Standen, 1991; Lippold & Burns, 2009; Lunsky, 2006). Connected with this notion, Lunsky (2006) proposes some people with intellectual disability may take less time to consider someone a friend than someone without disability. However, in more recent research, Callus (2017) found people with intellectual disability identified relationships, including those with paid support staff, as friendships when there was an element of reciprocity. Such reciprocity may adjust the power imbalance that usually exists.

The setting in which people with intellectual disability make and maintain relationships is another area of importance. Emerson and McVilly (2004) found friendship activities are more likely to occur in a public area rather than at home for people with intellectual disability. Callus (2017) proposes this may be due to the settings in which individuals form friendships, as these are often restricted or segregated settings such as disability service organisations and supported workplaces. When discussing friendship activities, individuals report restricted options when they want to spend time with friends outside of segregated settings (Knox & Hickson, 2001), and that it is important to have their own space or house so they can invite their friends over and have privacy (Bane et al., 2012; Fulford & Cobigo, 2016). Bane et al. (2012) also found limited transport options, particularly at night, restricted participants' ability to spend time with their friends or do activities together in public spaces. Simplican, Leader, Kosciulek, and Leahy (2015) found family members sought out segregated settings as they were seen as safer than non-segregated settings.

A body of work has been concerned with measuring and understanding the social networks of people with intellectual disability. Traditionally, it was thought that people with intellectual disability had very small networks often involving only two to three people (Robertson et al., 2001; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). The findings of this research came from proxy respondents; often paid support staff completed surveys about the social networks of the individuals they supported (e.g., Lunsky & Benson, 1999; Robertson et al., 2001). More recently, research that engaged with people with intellectual disability themselves has reported larger social networks, with up to 30 members (Forrester-Jones et al., 2006; van Asselt-Goverts, Embregts, & Hendriks, 2013). For example, Forrester-Jones et al. (2006) interviewed 213 people with intellectual disability using the Social Network Guide, a tool developed for people with mental health challenges and based on other well-established social network tools, to map their social networks and found the average network comprised of 22 network members. Networks consisted mostly of people with intellectual disability and paid support staff with a small number of members from outside the disability community.

Network members often include paid support staff, family members and friends who also have intellectual disability (Forrester-Jones et al., 2006; Jahoda & Pownall, 2014; Kamstra, van der Putten, & Vlaskamp, 2014; van Asselt-Goverts et al., 2013), although little is known and understood about the provision of social support by informal and formal supports. However, it is clear that many people with intellectual disability would rather strengthen their existing relationships than increase the number of people in their social networks (van Asselt-Goverts, Embregts, & Hendriks, 2015). Individuals would like to see their family and friends more often (Department of Health Victoria, 2011), but multiple barriers to seeing friends or family exist (e.g., lack of transport options, lack of support to meet others outside of home) (Bane et al., 2012; Department of Health Victoria, 2011).

Consistent with larger networks, people with intellectual disability report having more friends when compared to reports by proxy (van Asselt-Goverts et al., 2013). This may be due to the different understandings of friendships held by support people and individuals, as previously discussed. In addition, the personal nature of relationships means it would be difficult to respond on an individual’s behalf accurately. Network size is also affected by social stability, or the level of change and continuity of an individual’s social relationships. This is an important consideration as some people may experience a high turnover of paid support staff (McConkey, 2005), which can be disruptive to the individual’s social connections, particularly when a relationship is not maintained (Callus, 2017).

Related to social networks are informal and formal relationships. As highlighted in Section 2.2, informal and formal supports are critical to understandings of social support for people with intellectual disability. However, contemporary notions of informal and formal relationships may not reflect the way individuals use, experience and engage in social support. Many people with intellectual disability rely on others to provide support related to their disability and some or all of this support may come from informal or formal supports and may challenge and blur boundaries. Additionally, engagement with disability-related support is usually ongoing for people with intellectual disability and occurs throughout an individual’s life. The level of support needs can change over time and through different life stages. The nature of support related to disability can be full of complexities. For example, family members or friends may step into roles where they provide personal care or provide support to organise engagement with service organisations. Meltzer (2017) found siblings of people with disability attempted to manage the disability-related support they provided in such a way so that they could have a normative sibling relationship. At times, this meant seeking formal supports and reframing the support they provided in terms of ‘help’ or ‘looking after’ to avoid describing themselves as carers.

In one of the few studies to investigate informal and formal support, Bigby (1997) collected data from 62 older people with ‘mild’ to ‘moderate’ intellectual disability. She identified two types of informal support: emotional and practical. Bigby (1997) further differentiated between 10 types of practical support provided by informal supports (for example, but not limited to financial management, adoption of formal or legal roles, mediating, negotiating and advocating with services). These types of informal practical support encompass common functions of practical support (e.g., financial support, providing primary care) but also functions related to advocacy and service provision that cannot be easily replicated by formal supports (Bigby, 1997). Some of these roles also represent support typically associated with being provided by formal supports.

In contrast to Bigby’s approach, Kamstra, van der Putten, Post, and Vlaskamp (2015) clearly defined informal and formal support as dichotomous. These researchers investigated the social networks of people with profound intellectual and multiple disabilities. They defined formal support as paid professionals who have clear job descriptions and informal support as non-professionals who have their own motivation for providing support to people with intellectual disability (Kamstra et al., 2015). This distinction does not account for the changing or overlapping roles of informal and formal supports highlighted by Bigby (1997) and others working with different population groups (Horowitz, 1985), but may be reflective of the experiences of people with intellectual disability with higher disability support needs. These studies highlight the complex nature of informal and formal support, particularly around overlapping roles.

The nature of formal support can complicate relationships developed between service users and paid support staff. Service users may identify paid support staff members as friends, but it is unclear if these relationships are reciprocated (Callus, 2017; Lippold & Burns, 2009), particularly because organisations set professional boundaries where personal relationships between service users and paid support staff are discouraged due to concerns of vulnerability (Forster, 2016). Adding to these complex relationships, people with intellectual disability who use formal support can be restricted in their choice of service provider and, when unhappy with the support they receive, can experience difficulties making changes to the staff or the service provider who support them (Bigby, 1998).

Improving social support for people with intellectual disability

As discussed above, certain elements of social support have been emphasised by researchers, including the size of networks, reciprocity of friendship, opportunities for friendship activities to occur in settings preferred by individuals and for the stability of social relationships to be relatively constant. However, given the complex and diverse experiences of social support, it can be difficult for researchers to implement interventions to improve these elements of social support. (van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014). Interventions aimed at increasing the social support and social networks have largely focused on children and adolescents (Carter & Hughes, 2005). Within research with adults, several studies have focused on an individualised approach (consistent with individual level definitions of social support) that situates the problem with the individual with intellectual disability. These approaches have included education sessions with adults aiming to improve their communication and skills to make and maintain bonding relationships (Campbell & Gilmore, 2014; McConkey, 2005; Wilson, McKenzie, Quayle, & Murray, 2014). Commonly these education session are set within a formal setting and may not easily translate into a real world setting (McConkey, 2005).

Other interventions have included matching programs that focus on making linking and bridging relationships between individuals and volunteers (without intellectual disability) with the aim of developing friendships. Jameson (1998) describes a long running program where volunteers and individuals with intellectual disability were matched, and if both parties were happy, entered into a year-long agreement. At the time of the research only 44% of volunteers were still in contact with their matched partner after a year. Matched friendship programs may be artificial as the partners are often matched by people in managerial roles rather than the friendship developing naturally. Accordingly, McConkey (2005) advocates for a different approach to improving social support whereby people with intellectual disability have an increased opportunity to develop existing bonding relationships. He recommends increasing the opportunities for activities that are conducive to promoting social interactions (e.g., going to the movies or out for meals, participating in shared interests and hobbies, or team sports) (McConkey, 2005).

Building on the elements of social support already described in this chapter, the literature reviewed in this section can be used to further derive a more nuanced understanding of social support for people with intellectual disability. In terms of the five categories of social support definitions identified by Hupcey (1998), research has focused on the function of social support and social networks of people with intellectual disability, with some research touching on the reciprocity of support. Additionally, key findings from the literature demonstrate that little is known and understood about the informal and formal social support provided by family and paid support staff. Likewise, the role of romantic relationships is often overlooked as are the personal and nuanced understandings of how friendships are formed and maintained. Additionally, relationships are often formed and maintained through segregated settings, where there is limited opportunity for friendship activities to occur in settings preferred by individuals and for the stability of social relationships to be relatively constant. Additionally, it was highlighted that social support can be positive or negative.

2.4 Mechanisms of social support and health

The multitude of elements, concepts and terminology briefly reviewed in the previous sections provide an essential foundation for understanding social support for people with intellectual disability. This understanding also lays the foundation for this thesis's approach to understanding physical activity as a health practice. With this in mind, it is important to now consider the mechanisms through which social support influences health.

Although a focus of the literature has largely been on demonstrating the benefits of social support on health (see Section 2.1), the mechanisms through which these benefits occur have also been investigated, albeit to a lesser extent. Researchers have identified many mechanisms through which social support may influence health (Stansfeld, 2005; Thoits, 2011), summarised in Table 2.1 below. Among the many mechanisms that researchers have identified, two are frequently highlighted by the literature: direct- and buffering effects (Stansfeld, 2005). The direct-effect mechanism supports the notion that positive, negative or lack of support directly effects health. The buffering-effect supports the notion that social support moderates the effects of a stressful experience on health (Stansfeld, 2005).

In addition to the two commonly described mechanisms of support, other mechanisms of support have been identified. Thoits (2011) provides a review of seven mechanisms identified in the literature through which social ties influence health. The first mechanism identified is *social comparisons*, when an individual is guided by and informs their norms by comparing themselves with people from a similar group. An individual may change their behaviour to fit within the norms of the group they identify with; this can be a change that affects health in a positive or negative way (Thoits, 2011). Alternatively, *social* *control* is when members of an individual's social network try to change an individual's behaviour, usually to positively impact health (Thoits, 2011). This mechanism can also have a negative effect when network members push too hard for change and the individual resists change or becomes resentful of it (Thoits, 2011).

The following mechanisms are related to the role of individuals within social relationships. *Behaviour guidance, purpose and meaning* relates to the role individuals identify as having in relationships (e.g., parent-child, friend-friend) and their behaviour within that role, which is informed by their normative understanding of that role. An individual may gain purpose and meaning in their life by knowing they are significant to another person (Thoits, 2011). Another mechanism through which social ties influence health is through *self-esteem* and self-efficacy. Individuals evaluate their performance in their role (i.e., as a friend, parent, colleague) by comparing themselves to people similar to them or by evaluating themselves through the eyes of others. Feelings of self-efficacy are positively associated with experiences of social support (Benight & Bandura, 2004). In turn, by believing themselves to be competent at their role, individual's mental health can improve (Thoits, 2011). Related to the self-esteem mechanism, *sense of control* also has an influence on health. Within an individual's role, there are tasks that need to be completed through which individuals gain a sense of control. This could also have a negative effect on health though limited sense of control or a loss of control (Thoits, 2011).

Moving on from roles in relationships, the *belonging and companionship* mechanism refers to the sense of acceptance and connection to other have that can influence health. This can be positive (companionship can positively influence health) or negative (lack of companionship can result in poorer health). The final mechanism identified by Thoits (2011) is *perceived social support*; the mechanism linking social ties to health through emotional, informational and practical support.

In the intellectual disability field, focus has been on understanding the relationship between stigma and the mechanisms of *social comparisons* and *self-esteem* (e.g., Jahoda & Markova, 2004; Paterson, McKenzie, & Lindsay, 2012). More recently, Stevens et al. (2017) investigated the physical activity and dietary choices of adolescents and drew on some of the proposed mechanisms discussed above. A key finding of the research related to self-efficacy; when participants believed themselves to be good at a physical activity they participated more in this activity. Conversely, when participants lacked confidence in their ability to do an activity they avoided that activity. Of particular interest was the way one participant increased his self-efficacy; he became more confident in his knowledge and skills regarding his diet and physical activity by learning online about the best way to achieve his goal to increase muscle mass.

Table 2.1 Proposed mechanism between social support and health adapted from Stansfeld (2005) and Thoits (2011).

Mechanism	**Description of mechanism**
Direct-effect	Social support directly effects health. Effect can be positive or negative.
Buffering-effect	Social support moderates the effects of stress on health.
Social comparisons	Social norms informed by social ties; individual may adjust behaviour or beliefs to match reference group. Effect can be positive or negative.
Social control	Attempts from social network members to change behaviour of an individual; mechanism may result in positive or negative change.
Behaviour guidance, purpose and meaning (mattering)	Relationship roles and obligations that inform an individual’s behaviour; an individual may identify with role and relate it to their significance to other people. Effect can be positive or negative.
Self-esteem	An individual’s beliefs about their competence and worth.
Sense of control	Within roles of relationships there are tasks to be completed and by completing these tasks a sense of control is developed. Effect can be positive (e.g., confidence to deal with tasks) or negative (e.g., not able to complete tasks may have limited sense of control).
Belonging and companionship	Connections to other people foster a sense of belonging, which implies inclusion of other group members. Additionally, companionship, having someone to share activities with can be a positive influence on health. Conversely, a lack of lack of companionship can mean poorer health.
Perceived social support availability	The mechanism linking social ties to health. Social support can be in the form of emotional, informational and practical support. Support may come during everyday life or major stressful events. Support can be positive or negative.

2.5 Conclusion

This chapter aimed to solidify understanding of social support as it relates to people with intellectual disability. Through this review, a nuanced understanding of social support for people with intellectual disability was developed, which will continue to be refined throughout this thesis. In addition, this chapter identified key questions to be addressed by the subsequent chapters of the thesis:

- In response to their specific experiences of social support, what are the specific understandings of social support for people with intellectual disability and what is the function of social relationships in their lives?
- What can we understand about the provision of social support by paid support staff, and family and friends?
- Do the mechanisms of social support identified by Thoits (2011) contribute to enhanced understanding of experiences of physical activity among this group?

The foundational understanding and key gaps highlighted in this chapter will be used to inform and stimulate discussion in the following chapter. The following chapter applies a health practices lens to the physical activity literature relating to people with intellectual disability to gain an understanding of the social context of individuals' practices.

Chapter 3 A health practices approach to understanding physical activity for people with intellectual disability

The benefits of physical activity are well established and include chronic disease prevention and management and mental health benefits (Haskell et al., 2007; Reiner, Niermann, & Jekauc, 2013; World Health Organization, 2010). Consequently, the Australian physical activity guidelines for adults recommend 150 to 300 minutes of moderate intensity physical activity each week (Department of Health, 2014), which is consistent with international guidelines (World Health Organization, 2010). However, most people with intellectual disability do not participate in sufficient amounts of physical activity to meet these guidelines (Department of Health Victoria, 2011; Temple, Frey, & Stanish, 2006). A review by Dairo, Collett, Dawes, and Oskrochi (2016) found on average, only 9% (range 0 to 46%) of adults with intellectual disability participate in sufficient physical activity. Although interest and research in this area is growing, little is understood about how to best improve physical activity participation for people with intellectual disability (Bartlo & Klein, 2011; Scott & Havercamp, 2016; Temple, Frey, & Stanish, 2017). This may be related to the fact that even less is known about the role that physical activity plays in the lives of people with intellectual disability, and how it is perceived and/or understood by individuals.

In the previous chapter, important elements of social support for people with intellectual disability were highlighted, which lay the groundwork for an understanding of the health practices approach taken by this thesis. Also explored were the mechanisms through which social support can mediate health. Some of these mechanisms will be explored in more detail here. By building on the concepts described in Chapter 2, this chapter completes the literature review needed to understand the key concepts and ideas guiding the research question for this thesis. In doing so, it also starts to generate the rationale for the need for an inclusive research approach to best understand health practices and the role social support plays in enhancing participation in physical activity. The research approach adopted by the thesis, inclusive research, is explored in Chapter 4, followed by Chapter 5, which describes the specific methods used through this doctoral research.

The chapter is presented in four sections. The first section briefly examines the literature on physical activity and research that has been conducted in this area involving people with intellectual disability. Section two of the chapter considers key limitations of contemporary health promotion and public health research in relation to physical activity for people with intellectual disability. The third section draws on this critique and presents the notion of health practices as an alternative approach to understanding physical activity. In the final section, a health practices lens is applied to physical activity research with people with intellectual disability.

3.1 A brief review of physical activity research and people with intellectual disability

The physical activity research field has traditionally focused on physical fitness among people with intellectual disability and other population groups (Stanish & Frey, 2008). Early research focused on understanding the effects physical activity (e.g., walking on a treadmill) has on physical fitness outcomes (e.g., Carmeli, Barchad, Masharawi, & Coleman, 2004; Varela, Sardinha, & Pitetti, 2001). Within the past 10 to 15 years, focus has shifted towards physical activity rather than physical fitness, with a particular focus on understanding factors influencing participation in physical activity and developing interventions to increase time spent on physical activity (Stanish & Frey, 2008). This research is important to frame the later discussion about taking a health practices approach, and as such, will be briefly reviewed below.

Factors shaping participation and engagement in physical activity

People with intellectual disability report multiple factors influencing their participation and engagement in physical activity, many of which are also experienced by people in other population groups. It is worthy to note that many of these barriers are similar to those experienced in relation to friendship activities, which were explored in Chapter 2: a lack of transport options (Bodde & Seo, 2009; Frey et al., 2005; Heller, Hsieh, & Rimmer, 2003; Taliaferro & Hammond, 2016); inclement weather (Frey et al., 2005; Mitchell et al., 2016; Stevens et al., 2017); a lack of motivation to being active (Heller et al., 2003; Mahy, Shields, Taylor, & Dodd, 2010; Temple, 2007); the financial costs associated with being active (e.g., cost of gym membership, cost of transport, cost of paid support staff) (Bodde & Seo, 2009; Frey et al., 2005; Hawkins & Look, 2006; Heller et al., 2003; Messent, Cooke, & Long, 2000; Temple, 2007); and lack of time to be active (Dixon-Ibarra, Driver, Vanderbom, & Humphries, 2016; Frey et al., 2005; Taliaferro & Hammond, 2016). People with intellectual disability have also reported concerns about injury resulting from being active or the effect physical activity has on their health and health conditions as well as not liking the physical effects of physical activity on their body (e.g., being out of breath) (Frey et al., 2005; Taliaferro & Hammond, 2016). Busy streets and traffic, being out in the dark and environmental factors that pose a risk to safety (e.g., uneven footpaths/sidewalks as tripping hazards) have also been raised as barriers (Bodde & Seo, 2009; Frey et al., 2005; Mitchell et al., 2016).

Individuals have also reported some factors that facilitate physical activity, including being outside and in a natural environment and enjoying the opportunity to “get out of the house” (Brooker, Mutch, et al., 2015, p. 39). As alluded to in Chapter 2, social support has been reported to be a facilitator of physical activity. Temple and Walkley (2007), in their focus groups with people with intellectual disability and their supports, found individuals enjoyed the social opportunities being active provided. Brooker, Mutch, et al. (2015) and Dixon-Ibarra et al. (2016) reported people with intellectual disability found the opportunity to interact and make connections with others through physical activity was a facilitator to being active. In addition to the enabling effect social support can have on physical activity, lack of social support can act as a barrier to being active. People with intellectual disability have discussed their need for guidance (i.e., being shown how to do stretches) and experiencing a lack of self-confidence (Frey et al., 2005), but paid support staff may lack the time and skills to facilitate opportunities to be active (Temple & Walkley, 2007). Additionally, individuals have reported wanting to participate in structured activities (Frey et al., 2005), however, support people have not known which programs exist in their local area (Taliaferro & Hammond, 2016).

People with intellectual disability may experience social support that restricts their capacity or desire to be active. Frey et al. (2005) and Taliaferro and Hammond (2016) found that the influence of protective support people and medical professionals inadvertently reinforced sedentary behaviours as they cautioned individuals not to overexert themselves and stressed personal safety. Overprotectiveness, paternalistic attitudes of key support people and risk averse organisations also have the potential to reduce opportunities for individuals to engage in physical activity (Alesi & Pepi, 2017; Bodde & Seo, 2009; Brooker, Mutch, et al., 2015; Farrell, Crocker, McDonough, & Sedgwick, 2004; Hawkins & Look, 2006).

Interventions aiming to increase physical activity

Efforts to increase physical activity participation have been limited in scope and sustainability (Temple et al., 2017). Previous efforts often did not acknowledge the wider environment within which people live; however, more recently, interventions have begun to acknowledge the importance of fitting into participants’ lives (e.g., Martínez-Zaragoza, Campillo-Martínez, & Ato-García, 2015). A brief review of the interventions attempting to increase physical activity for people with intellectual disability is presented below.

Most intervention programs have focused on increasing physical activity and fitness though the provision of access to exercise programs based at community centres or workout equipment, either at their home or a disability organisation (Brooker, van Dooren, McPherson, Lennox, & Ware, 2015; Temple et al., 2017). However, the sustainability of these programs was rarely considered and generally access to the equipment or exercise programs ceased at the completion of the interventions (Brooker, van Dooren, McPherson, et al., 2015). For example, McDermott et al. (2012) ran an eight week education intervention with optional walk, which concluded at the end of the research. The intervention content in this study had been continuously revised when participants had trouble with concepts but did not result in a sustained change in behaviour at 12 month follow up.

The focus of programs is often on health education or promotion and include physical activity, nutrition and weight loss components (Heller, McCubbin, Drum, & Peterson, 2011). Some studies reported education sessions using interactive lessons to deliver the content (e.g., role playing) that were tailored to the needs of people with intellectual disability (Bazzano et al., 2009; Bodde, Seo, Frey, Lohrmann, & van Puymbroeck, 2012; Mann, Zhou, McDermott, & Poston, 2006). Participation in physical activity during the program was a key component of most of these interventions. Some programs included walks after the sessions (Ewing, McDermott, Thomas-Koger, Whitner, & Pierce, 2004; Mann et al., 2006), exercise sessions at local parks or fitness centres (Bazzano et al., 2009) and demonstrations and practicing of exercises and stretches in the sessions (Bodde, Seo, Frey, Van Puymbroeck, & Lohrmann, 2012; McDermott et al., 2012). Increasingly, there is a shift away from group programs to an individualised approach. Melville et al. (2015) individualised interventions for each participant; participants received three physical activity consultations based on behaviour change techniques, written materials (for participants and their support people) and an individualised structured walking program. However, the program did not result in a change in behaviour at six months follow up (Melville et al., 2015).

Additionally, some programs actively sought to include the participant's support people. This sometimes involved a specific component for support people (Bergström, Hagströmer, Hagberg, & Elinder, 2013) or their involvement in the process of the program (e.g., being present at meetings or sessions, encouraged to be active with participants)

(Martínez-Zaragoza et al., 2015; Melville et al., 2015). Bergström et al. (2013) targeted paid support staff working within group homes, who received an education program aimed at improving their health promotion work, and within each house a staff member was nominated as a health ambassador. The purpose of this role was to provide health information for members of the house (Bergström et al., 2013). Marks, Sisirak, and Heller (2012) took this approach a step further and designed a health promotion program aimed at paid support staff of disability support organisations. Staff attended training workshops where they learnt about physical activity, exercise and nutrition for people with intellectual disability and how to develop tailored plans to improve these behaviours of the people they supported (Marks et al., 2012). Arguably, these interventions attempted to change the social norms in the organisation to influence behaviour change. This reflects the *social comparisons* mechanism, discussed in Chapter 2, whereby individuals may adjust their behaviour to match new norms, and the *social control* mechanism whereby social network members (in this case paid support staff) attempt to change the behaviour of individuals (Thoits, 2011).

3.2 Key limitations of approaches to understanding physical activity

As this brief review of the literature demonstrates, within health promotion and public health research, two approaches have dominated research efforts to understand and promote participation in physical activity: individual and community level approaches (Marks & Sisirak, 2014; Scott & Havercamp, 2016). Traditionally, individual behaviours grounded in behavioural psychology have been the focus of physical activity related interventions and research (Scott & Havercamp, 2016). These interventions frequently involve an educational component that actively promotes the benefits of being active and engages participants in discussions about how to increase their physical activity (e.g., Bazzano et al., 2009; Bodde, Seo, Frey, Lohrmann, et al., 2012; Mann et al., 2006). They emphasise intra-individual factors, such as knowledge of the benefits of being active, motivation to be active and autonomy in decision making about being active, as key drivers for physical activity (Holman, Lynch, & Reeves, 2017). An individual level approach places the onus of responsibility on individuals to participate and assumes people can make rational and autonomous decisions and choices about their behaviour (Baum & Fisher, 2014). Non-participation is frequently seen as a deficit in individual decision making (Mielewczyk & Willig, 2007).

There has been some attempt to understand and acknowledge barriers to physical activity participation through the integration of community level approaches to interventions (e.g., Ewing et al., 2004; Marks et al., 2012). This type of approach has primarily been used in conjunction with an individual level approach and often focuses on reducing or removing barriers to physical activity. Many of these approaches focused on increasing opportunities for physical activity through the provision of access to exercise based programs, by going on a group walk or identifying opportunities in the local area for participants (e.g., Bazzano et al., 2009; Mann et al., 2006). Additionally, some approaches incorporated the use of behaviour change strategies, a common approach used in the wider population that incorporates individual level and community level approaches including addressing social support (e.g., Jones et al., 2006; Melville et al., 2015). In the literature reviewed above these efforts often ceased at the conclusion of the research (e.g., Ewing et al., 2004; McDermott et al., 2012) and only a small number of studies worked towards capacity building to ensure sustainable change (Marks, Sisirak, & Chang, 2013; Martínez-Zaragoza et al., 2015).

These approaches are limited in several ways. In particular, the focus on individual perspectives and choices often over-simplifies the complex set of practices and context that surround people with intellectual disability. Many people with intellectual disability receive support across various aspects of their lives; the nature of this support may limit an individual’s ability to exercise self-determination. Disability-related support is full of complexities and the ethos of support provision may differ across family members, paid support staff and organisations, resulting in a varied range of experiences. Moreover, while disability-related support aims to promote independence and support the individual to engage and participate actively in society, some support providers may take a more risk adverse approach or restrict the autonomy of the individual with intellectual disability.

Additionally, these approaches rarely acknowledge broader social factors such as the social determinants of health and their influence on health and health outcomes (Baum & Fisher, 2014; Frohlich, Corin, & Potvin, 2001). These social factors reflect the “conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life” (World Health Organization, 2014). A social determinants of health approach advocates for change to occur at a structural level, often through policy change rather than individual behavioural change (Baum & Fisher, 2014). People with intellectual disability are impacted by a range of complex social factors that are associated with poorer health outcomes (Emerson et al., 2011). For example, people with intellectual disability are often excluded from the workforce or rely on welfare payments (Emerson et al., 2011), resulting in low income, financial instability, poorer housing and therefore poorer health outcomes (Wilkinson & Marmot, 2003). Often people with intellectual disability experience systemic barriers to accessing healthcare and even exclusion from health promotion initiatives (Emerson et al., 2011; Reynolds, Stanistreet, & Elton, 2008). However, although the social determinants of health is useful for acknowledging broad structural factors that undermine meaningful participation in society, it typically views disability as an outcome measure (e.g., disability-free life expectancy) rather than as part of the context of an individual's experiences (Emerson et al., 2011).

3.3 Introducing the notion of health practices

In response to learnings gained from the review of approaches provided above, the notion of health practices has been adopted within this thesis to understand physical activity. A health practices approach seeks to understand the broader social and individual contexts that impact on health and health related behaviours (Mielewczyk & Willig, 2007). Health practices are grounded within social practice theory, which acknowledges that a behaviour does not occur in isolation. Instead, a set of practices form the action related to the behaviour (Delormier et al., 2009). This approach explores the dynamic between structure and agency to consider practices within the broader social context in which they occur (Nettleton & Green, 2014). Structure represents the rules and resources in society that shape individuals' decisions and choices (Frohlich et al., 2001). Agency reflects an individual's ability and capacity to exercise independent choice and control over their decisions (Frohlich et al., 2001). Within social practice theory, structure and agency are interdependent factors rather than mutually exclusive. An individual's decisions and choices are not solely influenced by the social structure nor are they made solely based on an individual's free will (Delormier et al., 2009; Nettleton & Green, 2014).

A key feature of health practices is that it goes beyond focusing on individuals and aims to understand the context in which the practice takes places (Frohlich et al., 2001; Mielewczyk & Willig, 2007). Social context, as a concept, is difficult to define and has been described as complex and hard to measure (Holman et al., 2017). Burke, Joseph, Pasick, and Barker (2009) define social context within a health practices framework as "socialcultural forces that shape people's day-to-day experiences and that directly and indirectly affect health and behaviour" (p. 56S). These forces can include historical or political processes, organisations and community, and social relationships. Each of the forces identified by Burke et al. (2009) can co-occur and influence each other, often influencing individual without their conscious knowledge. In summary, social context in this thesis has been defined as including the social determinants of health, social structures, historical and political processes, community, organisations and social support. Consistent with the definitions reviewed above, it is acknowledged that components of social context are interconnected and can influence each other.

To investigate health practices, Mielewczyk and Willig (2007) emphasise the importance of using methods that “are capable of investigating meaning and context” (p. 829). Horrocks and Johnson (2014) reflect that the majority of health practices research has used qualitative inquiry using a participatory approach. This allows for the development of socially grounded understandings about the topic under investigation. In intellectual disability research, this type of approach is reflective of inclusive research. Inclusive research is often qualitative in nature and allows, by focusing on the perspectives and experiences of people with intellectual disability, the context of individuals lives to be captured (Walmsley & Johnson, 2003).

Within this thesis, a health practices approach is used to describe physical activity as the social practice involved in being active. This is particularly important for understanding physical activity undertaken by individuals with intellectual disability given the potential for a diverse range of experiences of choice, the experience of receiving and potentially relying on disability support to be active, and the experience of disablement when seeking to be active (e.g., inaccessible physical activity options, discrimination). As an example, an individual with intellectual disability may integrate physical activity into their daily routine by walking to catch public transport to work. The individual enjoys this walk as it fosters a sense of independence and autonomy. Without this walk, they would have to rely on someone else, such as a paid support staff member, to assist with transport. To be able to do this walk, the individual received support and developed the necessary skills and independence (i.e., a support person helped the individual plan the walking route, the route was practiced to build confidence, the individual and support person talked through possible scenarios such as missing the bus). Considering the walk through the lens of health practices allows the researcher to understand the context in which a health behaviour, in this case physical activity, occurs and the role of this behaviour in the life of an individual. It recognises the complex set of actions undertaken by the individual including the social relationships that supported this practice.

3.4 Applying a health practices lens to physical activity literature

As discussed in the first section of this chapter, efforts to increase physical activity participation for people with intellectual disability have focused on individual and community level understandings of physical activity without consideration of the context in which the physical activity occurs. The literature related to factors shaping participation and engagement in physical activity was identified as a means to gain insight into the social context in which people with intellectual disability experience physical activity. The following section will review relevant literature by applying a health practices lens to understand the social context of physical activity for people with intellectual disability.

As highlighted in Chapter 2, of particular importance to understanding the social context of physical activity and the role social support can play in being active is the experience of support related to disability. The context of using, receiving and requiring disability-related support adds to the complexity of social experiences for people with intellectual disability. The role of disability support is unique; support people (i.e., paid support staff, family members) have the potential to be in a position to promote health and health practices such as physical activity. As discussed in previous chapters, disability service organisations and paid support staff can play a large role in some individuals' lives and their health practices. This presents an opportunity where the mechanisms in which social support influences health can be used to influence physical activity participation. For example, by providing an environment where the social norms reflect healthy behaviour, the *social comparisons* mechanism proposes individuals may adjust their behaviour to match the norms. Other mechanisms which may be in play in this situation include *social control*, *behaviour guidance, purpose and meaning* and the *sense of control* (Thoits, 2011).

Despite disability service organisations and paid support staff having a unique opportunity to support the health of individuals they support, this is often not the case. Health and support related to health is often not prioritised by organisations or their funding (O'Leary, Taggart, & Cousins, 2018). Support people may have a lack of knowledge and/or skills relating to supporting and promoting health (Melville et al., 2009). Policies relating to health have also been found to be lacking; a review of paid support staff role descriptions found health and health related tasks were not listed (O'Leary et al., 2018). This lack of support at an organisational level can result in limited staff time or availability to promote and support health related activities and may prevent the development of social norms supportive of these practices.

As already discussed, disability support organisations and support people (both formal and informal, including family members) may pose restrictions or barriers to participating in physical activity based on paternalistic, protective or risk adverse attitudes towards the individuals they support (Frey et al., 2005; Taliaferro & Hammond, 2016). Farrell et al. (2004) reported participants of Special Olympics found the policies of the organisation to be rigid; participants reported coaches did not support participant's autonomy and were strict. Hawkins and Look (2006) also found organisations required support staff to complete risk assessments, which acted as a barrier to supporting people to be active as it was seen as too time consuming to gain approval. People with intellectual disability have been cautioned not to overexert themselves and the importance of personal safety may be stressed by support people and medical professionals (Frey et al., 2005; Taliaferro & Hammond, 2016). These attitudes can inadvertently reinforce sedentary behaviours.

Other aspects of social context that have been explored by the literature include transport options and safety. People with intellectual disability have identified transport as a barrier to participating in physical activity (Bodde & Seo, 2009; Frey et al., 2005; Heller et al., 2003; Taliaferro & Hammond, 2016). Participants in Frey et al. (2005) reported they faced "a lot of transportation issues" (p. 247) due to a lack of options. Transport is an important consideration for community based physical activity options that require people to travel to participate. Transport and support related to transport (e.g., a paid support staff member may help identify the bus route) is an important part of the context of why people may or may not participate in community based opportunities. Another barrier experienced by people with intellectual disability is being able to safety participate in physical activity. Individuals have voiced concerns about busy streets and traffic, being out in the dark and feeling unsafe in their local neighbourhood (Bodde & Seo, 2009; Frey et al., 2005). These safety barriers could be related to broader influences. For example, often people with intellectual disability have low incomes and may live in lower social economic areas (Australian Bureau of Statistics, 2014), which may have higher rates of crime resulting in the individuals feeling unsafe in their local community.

Physical activity and social support

It is widely accepted in other population groups that social support plays a role in physical activity participation (McNeill, Kreuter, & Subramanian, 2006; Trost, Owen, Bauman, Sallis, & Brown, 2002; Yu et al., 2011). The evidence base is much smaller for people with intellectual disability, potentially because of the focus on causative factors rather than health practices.

Adults with intellectual disability report that having someone to be active with and to show them how to be active (i.e., demonstrating stretches) is an enabler of physical activity (Alesi & Pepi, 2017; Frey et al., 2005; Temple, 2009). This may speak to the perceptions of people with intellectual disability that they are viewed as needing support; individuals may embody this belief and think they need specific demonstrations or training on how to engage in physical activities. This experience is consistent with the *self-esteem* mechanism described in Chapter 2 where an individual's beliefs about their competence and abilities influences their health (Thoits, 2011). In contrast, people with intellectual disability report enjoying the connections and interactions they have with others while engaging in some physical activities (*belonging and companionship mechanism*) (Brooker, Mutch, et al., 2015; Dixon-Ibarra et al., 2016; Temple & Walkley, 2007).

3.5 Conclusion

In the previous chapter, important elements of social support for people with intellectual disability were highlighted. By building on the concepts described in Chapter 2, this chapter completed the literature review needed to understand the key concepts and ideas guiding the research question for this thesis. In doing so, it also highlighted the best research approach to understand health practices for people with intellectual disability, inclusive research. Inclusive research is explored in the next chapter. Chapter 5 describes the specific methods used throughout this doctoral research.

Chapter 4 A methodological approach informed by inclusive research principles

The preceding chapters reviewed the social support and health practices literatures as they relate to people with intellectual disability and highlighted the importance of considering the context of behaviours, experiences and social support through the perspectives of people with intellectual disability. The reviewed literature indicated that health practices research is often embedded in a participatory approach using qualitative methods (Horrocks & Johnson, 2014). The primacy of qualitative inquiry was also highlighted by Williams et al. (2004) who identify it as a valuable methodological tool for investigating social support within distinct population groups. Within the field of intellectual disability, qualitative participatory research often sits under the umbrella of inclusive research (Walmsley & Johnson, 2003). An inclusive research agenda, which actively engages with people with intellectual disability, is fundamental to intellectual disability research, particularly in light of the historical treatment of this group by researchers (Walmsley & Johnson, 2003). Traditionally, research has been conducted *on* people with intellectual disability rather that *with* them (Kiernan, 1999). As a consequence, people with intellectual disability have not been actively engaged as researchers or participants, but instead research decisions have been made by those who do not have intellectual disability, and data has been gathered from proxy respondents who speak for those with intellectual disability (Kiernan, 1999; Walmsley & Johnson, 2003). Due to the nature of intellectual disability (e.g., some people have limited verbal communication, others may not be able to actively consent to research) many challenges can arise and extra effort on the part of the researchers is needed to engage, support and recruit individuals into research (Lennox et al., 2005). Perhaps due to the challenges associated with conducting research, this population group is often actively and passively excluded from mainstream medical and public health research (Brooker, van Dooren, Tseng, et al., 2015; Feldman, Bosett, Collet, & Burnham-Riosa, 2014).

Inclusive research attempts to reduce the barriers people with intellectual disability face in research and ensure their needs are placed at the centre of research decisions and processes (Walmsley & Johnson, 2003). As a result, inclusive research actively seeks to engage people with intellectual disability as both participants and researchers. However, despite general understanding of the spectrum of inclusive research approaches that engage people with intellectual disability as *researchers* (Walmsley & Johnson, 2003), the literature provides limited guidance on the translation of inclusive research into practices that can be applied in the field and used to guide the engagement of people with intellectual disability as *participants* (e.g., Heller, Nelis, Collins, & Pederson, 2011). To fill this gap and identify inclusive qualitative research practices, a systematic review of the empirical literature was conducted. The following chapter presents the results of this review and provides a blueprint of the inclusive research practices that qualitative researchers can use as a starting point when applying inclusive research principles to their research. This blueprint will be used to guide this thesis.

The following chapter is presented in two sections. The first provides a foundational understanding of inclusive research approaches as they relate to qualitative methodologies. Specifically, it considers the work of Walmsley and Johnson (2003) and Bigby et al. (2014) and the development of a spectrum of engagement of people with intellectual disability as researchers. This section then moves to explore the practices that underpin inclusive research and the methods used to guide qualitative research engaging people with intellectual disability as research participants. Section two of this chapter presents a review of qualitative literature with the aim of identifying research practices that are inclusive of people with intellectual disability as *participants*. This review informed the development of a blueprint of inclusive research practices that qualitative researchers can use as a starting point when embodying the key principles of inclusive research. The blueprint will guide the thesis and my research with people with intellectual disability. More broadly, this review addresses the first aim of the thesis: to identify good practice when conducting qualitative research with people with intellectual disability.

Before proceeding it is important to provide some clarification of the terminology used throughout this chapter and the thesis. The term *inclusive research* is an umbrella term that incorporates both inclusive research approaches and inclusive research practices. *Inclusive research approaches* describe the inclusion and engagement of people with intellectual disability as *researchers,* whereas *inclusive research practices* describe the application of specific methods and practices to engage people with intellectual disability as *participants* in research.

4.1 Inclusive research

Broadly, inclusive research as a methodology values and seeks input from people with intellectual disability as researchers and participants. The key principles of inclusive research reflect research that meaningfully engages participants, is participant focused, and seeks the active participation of people with intellectual disability in all research processes (Bigby et al., 2014; Walmsley & Johnson, 2003). Inclusive research has its origins in the disability rights movement and the social model of disability (Walmsley & Johnson, 2003). As described in Chapter 1, disability activists demanded a ‘nothing about us without us’ approach that argued researchers should no longer conduct research ‘on’ people with disability, and should instead include people with disability in meaningful ways across all research practices (Charlton, 2000; Stack & McDonald, 2014). Using this perceptive, researchers must actively and genuinely engage with people with disability in decision-making related to research and knowledge production about disability (Charlton, 2000). Moreover, an emancipatory approach, which engages people with disability as researchers and uses research findings to generate change, is essential (Zarb, 1995). This approach recognises people with disability as valuable contributors and drivers of research, whose voices must be captured (Kiernan, 1999).

Throughout the development of the social model of disability and shift towards emancipatory research, the focus was largely on physical disability without explicit consideration of people with cognitive impairments (Walmsley & Johnson, 2003). Nonetheless, researchers began to engage people with intellectual disability in research processes in the late 1980s and 1990s (Walmsley & Johnson, 2003). This led to the conceptualisation of inclusive research, a term coined by Walmsley (2001), as an umbrella term describing “a range of research approaches that traditionally have been termed ‘participatory’, ‘action’ or ‘emancipatory’” (Walmsley & Johnson, 2003, p. 10). Inclusive research represents a perspective where people with intellectual disability are more than just participants or respondents but are active co-producers of research.

The publication of Walmsley and Johnson (2003) seminal book *Inclusive research with people with intellectual disabilities: Past, present and futures* has fuelled increased interest and use of inclusive research in recent years (Crowther, Rillotta, Whitehead, Knox, & Ellison, 2016). Consequently, a dialogue has begun among researchers on the best ways to use and progress inclusive research in the intellectual disability field (Bigby et al., 2014; Frankena et al., 2018; Frankena et al., 2016; Nind, 2014).

Approaches of inclusive research: A spectrum

Walmsley and Johnson (2003) intended inclusive research to be broad and allow for blurred and shifting boundaries (Nind, 2014). However, those seeking to adopt an inclusive research approach often experience difficulties due to the broad nature of the term, which can be interpreted and applied in quite different ways (Bigby et al., 2014). Increasingly, inclusive researchers have pushed for clearer conceptualisations of the approaches used (Bigby et al., 2014; Frankena et al., 2016). The following section describes the different approaches to inclusive research informed by the work of Walmsley and Johnson (2003) and Bigby et al. (2014) from the perspective of research engaging people with intellectual disability as *researchers*. These approaches occur on a spectrum from a minimal to comprehensive approach (see Figure 4.1). This understanding of inclusive research provides a foundational basis that is used to inform and guide the engagement of people with intellectual disability as *participants* in the next section.

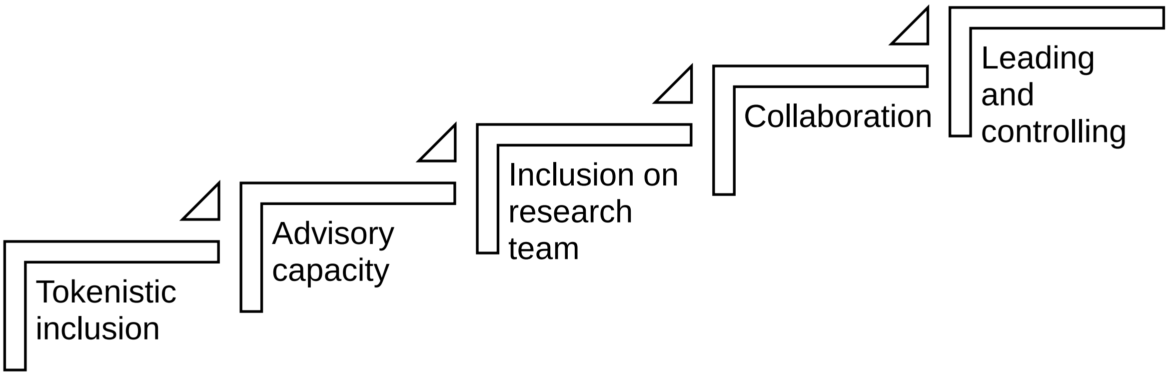

Figure 4.1 Spectrum of approaches to inclusive research.

At the first stage of the spectrum Walmsley and Johnson (2003) warn against *tokenistic inclusion* of people with intellectual disability when conducting research. Tokenistic inclusion occurs when the participation of people with intellectual disability as researchers is not meaningful, their views are not actively sought or used, nor is there sufficient time or support provided to ensure meaningful participation (Frawley & Bigby, 2011).

At the next step up the spectrum, Bigby et al. (2014) and Walmsley and Johnson (2003) describe the engagement of people with intellectual disability in an *advisory capacity*, which may include involvement with the research team in setting research priorities, making research decisions (e.g., research design, recruitment strategies, data collection, data analysis and dissemination), or providing advice on key issues. Engagement of people with intellectual disability must be active and genuine to ensure their experiences and views are appropriately acknowledged and considered; however this approach can be undermined by a number of factors including the involvement of ‘usual suspects’ (i.e., people who have a pre-existing relationship with the research team) (Frawley & Bigby, 2011) in the research team. As Aspis (2000), an individual who identifies as a person labelled with learning difficulties[1] notes, she is often not engaged by researchers because she is known to challenge and ask difficult questions. Researchers may also recruit people with intellectual disability based solely on their lived experience of intellectual disability rather than considering their broader capacity and experience (e.g., as someone engaged in the rental housing market). Ultimately, an advisory approach hinges on the commitment of researchers who determine how the advice they receive is incorporated into research processes (Bigby et al., 2014).

A step closer to a comprehensive approach is including people with intellectual disability on the *research team*. Research team members with intellectual disability are generally involved as paid employee in the day-to-day process of research (e.g., survey development, focus group facilitation), to enhance the relevance, quality and accessibility of research for people with intellectual disability. Moreover, this approach acknowledges the diverse lived experiences of people with intellectual disability in the research process (e.g., Butler, Cresswell, Giatras, & Tuffrey-Wijne, 2012). Step five on the inclusive research spectrum involves *collaboration* or co-research (Bigby et al., 2014; Walmsley & Johnson, 2003). Co-researching involves people with and without intellectual disability pooling their expertise to work collaborative in equally valued roles (Walmsley & Johnson, 2003).

The final stage of the spectrum research is *led and controlled* by researchers with intellectual disability who "initiate, lead and execute their own research about issues that are important to them" (Bigby et al., 2014, p. 6). This approach is rarely adopted, but has been used by advocacy groups when a problem or issue is identified (Bigby et al., 2014; Walmsley & Johnson, 2003).

4.2 Mapping the literature: Developing a guide to good practice qualitative research

The guiding methodology adopted in this review, inclusive research, was adopted as it attempts to reduce the barriers people with intellectual disability face in research and ensure their interests and needs are placed at the centre of research decisions and processes (Walmsley & Johnson, 2003). As discussed above, Walmsley and Johnson's (2003) work provides a clear foundation for understanding an inclusive research approach

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[1] This language is used purposefully by Aspis to acknowledge the identity of learning difficulty has been imposed on her by society and reflects the social model of disability's use of language in the United Kingdom where she lives (Aspis, 1999, 2000).

that engages people with intellectual disability as researchers; however it is also essential to understand how we can use inclusive research practices to engage people with intellectual disability as *participants* in research. While the two are clearly synonymous, engaging people with intellectual disability as researchers is undoubtedly intended to inform and drive inclusive research practices. However, it is clear that for many, an inclusive research approach may not be central to the research agenda while for others it may not be feasible. For this reason it is essential to provide a starting point that translates the principles of inclusive research – participant focused, seeking meaningful engagement and active participation (Walmsley & Johnson, 2003) – into practices that can be applied in the field to ensure the active participation of people with intellectual disability in research.

At the commencement of this thesis, I sought to identify a guide that translated the key principles of inclusive research into practice when conducting qualitative research; however, beyond work considering participatory research broadly, I was unable to identify a guide specific to the field of intellectual disability. A review by Nind (2008) drew attention to the challenges of conducting qualitative research with people with learning, communication and other disabilities and provided advice on how to address key issues associated with communication. Another review by Beail and Williams (2014) highlighted the challenges of conducting qualitative research in the field and recommended practices to increase participation, but neither review systematically mapped the literature or offered concrete guidance on conducting rigorous, high quality qualitative research that embodied the key principles of inclusive research with people with intellectual disability. To constructively build on these reviews and further address the research gap that remained, I systematically reviewed the literature to identify research practices that were inclusive of people with intellectual disability as participants of qualitative research. The following section describes the methods used to conduct the systematic mapping of qualitative research conducted with people with intellectual disability. It also examines the inclusive research practices identified across the literature and draws on these results to inform a blueprint of inclusive research practices for qualitative research that will be used to inform the research for this thesis.

Methods

This review aimed to identify good practice when conducting qualitative research with people with intellectual disability in line with the key principle of inclusive research; research that is participant focused, seeks meaningful engagement and active participation of people with intellectual disability in all research processes.

Search strategy

Database searches were conducted (CINAHL, Health Source: Nursing/Academic Edition, Medline (via Pubmed), PsycINFO, Scopus and Web of Science) using key terms related to ‘intellectual disability’ and ‘qualitative method’, with results limited to studies published between 2004 and 2015. The contents pages of key qualitative journals (*Qualitative Health Research* and *Qualitative Research*) and intellectual disability journals (*Journal of Applied Intellectual Disability Research* and *Journal of Intellectual Disability Research*) were also searched. Reference lists were manually searched for eligible articles. A cited reference search of key articles was conducted using Web of Science. An example search strategy is presented in Table 4.1 and PRISMA checklist (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) is presented in Appendix B.

Table 4.1 Example search strategy.

Database	Search terms	Search date	Search results
Web of Science	(“developmental disability*” OR “Down syndrome” OR “intellectual disability*” OR “learning disabilit*” OR “learning difficult*” OR “learning disorder*” OR “mental* retard*” OR “intellectual handicap*” OR “intellectual impair*” OR “mental* handicap”) AND (qualitativ* OR interview* OR “focus group*” OR observation* OR Photovoice OR “photo novella” OR “life story” OR “life history”)	18/11/2015	4928

Selection criteria

Eligible peer-reviewed studies had to report qualitative methods used to conduct research with adults with intellectual disability. Articles were excluded if: (i) they did not describe a qualitative method; (ii) the main informants were not adults with intellectual disability and; (iii) studies were not published in English. No exclusions were made based on discipline or subject matter. The review aimed to look beyond the health literature, which has traditionally been dominated by a clinical voice and take a nuanced approach to health consist with the social model of disability.

All identified articles were assessed for their relevance to the selection criteria by reviewing titles and abstracts. Potentially relevant articles were read in detail. Issues relating to the inclusion of an article (e.g., articles that were unclear about methods or participants) were discussed among the research team. It was outside the scope of this study to contact authors for more details. Articles that did not report methods and results were excluded.

The search strategy identified 15 868 articles, of which 5 850 were duplicates. The remaining articles (n=10 018) were reviewed at the title and abstract level, and articles were excluded based on the selection criteria. In total, 322 articles were included in the review (see Figure 4.2).

Data analysis

A framework approach to data analysis was taken in this review. It allowed for an in-depth understanding of the diverse range of literature. Framework analysis is a process used for data analysis in primary qualitative research which in recent years has been adapted to conduct synthesis of qualitative studies (Dixon-Woods, 2011). It allowed for an applied, practical understanding of the methods used to conduct qualitative research with people with intellectual disability (Ritchie & Spencer, 1994; Srivastava & Thomson, 2009).

Data analysis began during data extraction, where familiarisation began and the emerging themes were noted. This process formed the initial thematic framework. The thematic framework was applied and regularly reviewed during data analysis. A data extraction table was developed based on the thematic framework that incorporated key overarching themes that occurred on three levels: a basic description of study design (e.g., methods, methodological approach, sample information); challenges/barriers experienced when working with people with intellectual disability (e.g., recruitment, identification of intellectual disability, consent and communication); and strategies that aimed to be inclusive of participants (e.g., in-depth information about the approaches researchers took to include participants with intellectual disability). The data was charted by themes to assist in the mapping and interpretation of the data. The analysis was a recursive process whereby I returned multiple times to the data and thematic framework to revise and synthesise themes.

Results

The results are presented in two sections. First, a brief descriptive summary of the 322 eligible articles is presented. Second, the key overarching themes identified in the thematic framework are presented.

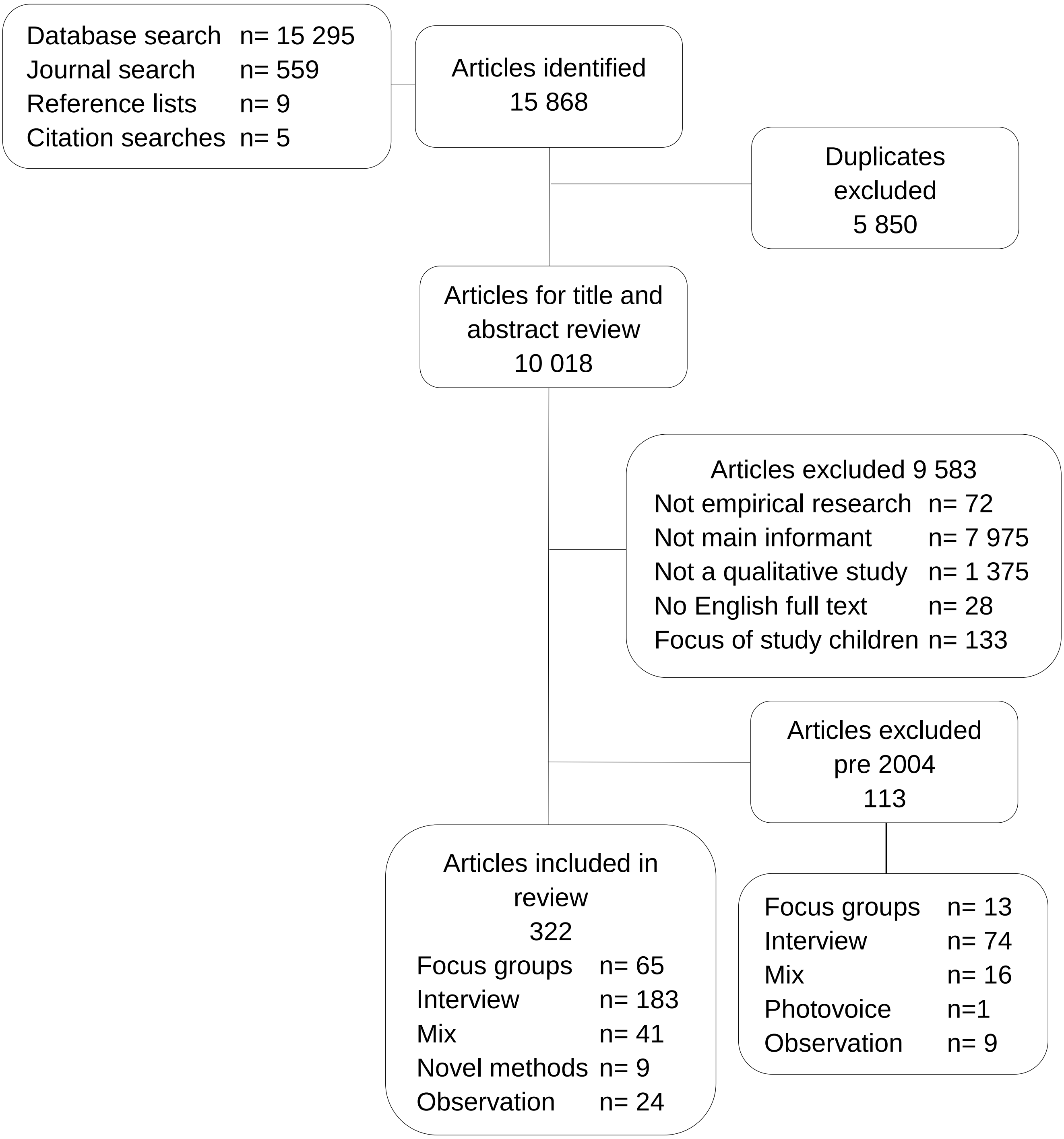

Figure 4.2 Flow of articles selected for review.

Description of extant qualitative research involving adults with intellectual disability

Interviews were the most common primary method employed (n=183), followed by focus groups (n=65), participant observation (n=24); and photovoice (n=7). Forty-one studies employed multiple methods (e.g., interviews, observation and photovoice). Less than one-third of studies grounded their research in theory, for example, inclusive research, ethnography, grounded theory, interpretative phenomenology or phenomenology, but the majority did not discuss broader methodological foundations. The most frequently investigated topics included health, social relationships, social inclusion, employment, education, accommodation, advocacy, parenting, and views and experiences of disability support staff and organisational services. The research was conducted internationally, with the most common countries of origin being the United Kingdom, Australia, United States of America, Sweden, the Netherlands and Canada.

Most studies were found to have gaps in their reported procedures or methods, including descriptions about how they: recruited participants, developed rapport and trust with participants and gate-keeping organisations, identified people with intellectual disability, and dealt with issues arising during the research process. Audit trails used to record analytical decisions were rarely described and the process of data analysis was sometimes unclear. However, across all studies, findings were generally supported by illustrative quotes from participants with intellectual disability.

Less than half of the studies reported level of disability or functioning of participants; most participants were identified as having ‘mild’ to ‘moderate’ intellectual disability with only a small number of studies (n=23) including or focusing on people with ‘severe’ disability. Level of disability was based on service organisations’ records, clinical or social records, government records of disability pension, membership of self-advocacy groups, and/or authors use of screening tools (e.g., Wechsler Abbreviated Scale for Intelligence (Psychological Corporation, 1999)). The American Psychiatric Association definition of intellectual disability (‘a limitation in intellectual functioning (an IQ score of below 70) and adaptive behaviour (e.g., communication, social skills, self-care) originating before 18 years of age’ (American Psychiatric Association, 2013)) was most frequently referenced. Researchers rarely drew on the social model of disability to define intellectual disability (i.e., describing the environments or structures that might be disabling to participants).

Research practices employed by researchers to include people with intellectual disability

A framework analysis of the articles identified a range of research practices including: *comprehensive consent processes, accommodating support people and gate-keepers, accommodating diverse communication styles, accommodating external factors, getting the timing right, building relationships and rapport with participants, considering the role of relationships, enhancing data analysis processes, closing the research loop and the use of advisory teams or researchers with intellectual disability in the research process.* Many of these practices were incorporated to address barriers to participation (e.g., facilitating consent and enhancing communication) and required only limited adaptation or modification of conventional research processes. However, a smaller number of practices, particularly those that focused on enhancing data analysis processes and closing the research loop appeared to be embedded in inclusive research approaches. For some of these studies, there was clear intersection of their practices and the inclusive approach they used, such as engaging people with intellectual disability as researchers or advisory team members. In short, the research studies that adopted multiple practices appeared to act in a manner that was consistent with the principles of inclusive research and mirrored some of the inclusive research approaches identified by (Walmsley & Johnson, 2003). The following discussion examines each of the practices in turn.

Comprehensive consent processes

The process of gaining consent is frequently identified as a key challenge for research in the field of intellectual disability. The majority of studies described investment in the development of information sheets and consent forms that were in a plain English format (e.g., Bennett & Cunningham, 2014; van Dooren, Lennox, & Stewart, 2013; Wilson, McKenzie, Quayle, & Murray, 2013). A number used pictures to convey the consent information (Akkerman, Janssen, Kef, & Meininger, 2014; Furness, Armitage, & Pitt, 2011; Martean, Dallos, Stedmon, & Moss, 2014). A small handful of studies acknowledged that participants had trouble reading – to address this a researcher read the information sheet and consent form to participants (Akkerman et al., 2014; Duperouzel & Fish, 2008). A handful of studies gave participants additional time to go over the information and consent process and encouraged them to discuss participation with family, friends and paid support staff (Chapman et al., 2012; Höglund & Larsson, 2013). Among studies that collected data over several time points a continuous consent process was sometimes used which involved researchers discussing the research and consent process at each meeting or data collection session with the participant (Duperouzel & Fish, 2010; Owens, Mistry, & Dyer, 2011; Read & Papakosta-Harvey, 2004).

One of the most innovative consent practices included the development of DVDs involving the research team, which included a researcher with intellectual disability discussing the research in a ‘Question and Answer’ format (Abbott & Burns, 2007; Butler et al., 2012; Pawson, Raghavan, Small, Craig, & Spencer, 2005). Pawson et al. (2005) filmed a mock scenario (e.g., what an interview would look like) of the data collection process to demonstrate what participants could expect from their involvement in the research.

Accommodating support people and gate-keepers

Family or paid support staff who assist individuals during data collection, particularly in interviews or focus groups, may often answer on behalf of the person, talk over them or influence their responses (e.g., Llewellyn & Northway, 2008; Schleiena, Brakea, Millera, & Walton, 2013). A small number of studies acknowledged the integral role these people can play and invested time in building the relationship with families and paid support staff to ensure open and ongoing communication processes about the research (Dias et al., 2012). This was particularly important in the studies that examined sensitive topics (e.g., cancer, dying and funerals) (Forrester-Jones, 2013; Tuffrey-Wijne, Bernal, & Hollins, 2008). Dias et al. (2012) also acknowledged the gatekeeper role that families and paid support staff can play and again worked to ensure these parties were well informed of the research and its progress to foster their support of participants' engagement. Similarly, Ellem and Wilson (2010) incorporated practices that kept family members and paid support staff informed including investing time to build trust and rapport with those parties to ensure they encouraged the participant to respond instead of answering on their behalf.

Accommodating diverse communication styles

Most researchers incorporated practices to enhance communication with participants, including the use of visual materials, visual scales and storytelling to clarify meanings, support interactions and facilitate discussions (e.g., Boyden, Esscopri, Ogi, Brennan, & Kalsy-Lillico, 2009; Brown & Gill, 2009; Butler et al., 2012; Caton et al., 2012; Forbat & McCann, 2010; Kramer, Kramer, García Iriarte, & Hammel, 2011; McDonald, Kidney, & Patka, 2013; Tuffrey-Wijne, Giatras, Butler, & Cresswell, 2012). Caldwell (2010) provided participants with an outline of interview questions prior to the interview. A small number of studies prepared alternative questions and prompts to guide interviews when key points were not understood (Duperouzel & Fish, 2010; Fitzgerald & Withers, 2013), whereas Abbott and Mcconkey (2006) and Gibbs, Brown, and Muir (2008) encouraged family members/paid support staff to assist with communication and interpret responses during the data collection.

Accommodating external factors

Researchers reported several external factors that needed to be considered when engaging people with intellectual disability in qualitative research including: transport and identification of appropriate venues that were familiar to participants or included private spaces for discussion (e.g., Ellem & Wilson, 2010; Gates & Waight, 2007; McDonald, 2012). Many frequently found it difficult to work around participants’ busy schedules and lives, particularly when organising focus groups through organisations that ran busy social programs (Adolfsson, Mattsson Sydner, & Fjellström, 2010; Forrester-Jones, 2013; Gates & Waight, 2007). To address these factors many enabled participants to choose the time and/or location of the interview, and supported participants in their decision on whether a support person was present or not (e.g., Finlayson et al., 2014; Herps, Buntinx, & Curfs, 2013; Kenyon, Beail, & Jackson, 2014).

Getting the timing right

A small number of researchers recommended spreading data collection over multiple sessions to give participants the opportunity to go home, reflect and formulate their responses (Höglund & Larsson, 2013; Todd & Read, 2010). Timing was also particularly important for the few researchers who conducted photovoice, such as Jurkowski and Paul-Ward (2007), who found participants had trouble recalling why they took the photo or why the photo was important due to the time delay between taking and discussing photos. A small number of studies highlighted the need to guide the timing and pace of the data collection based on the needs of participants (Ellem & Wilson, 2010; Gates & Waight, 2007; Stalker, Jahoda, Wilson, & Cairney, 2011). Boyden et al. (2009) provided participants with additional time to respond to questions and allowed time for breaks and interruptions. Gates and Waight (2007) incorporated additional time into focus groups to ensure conversations were appropriately paced.

Building relationships and rapport with participants

A common approach used by many researchers, particularly those using multiple points of data collection, was to develop rapport and trust with participants to enable them to feel comfortable and share their experiences (e.g., Gates & Waight, 2007; Jahoda & Markova, 2004; McDonald et al., 2013; Mulcahy, 2012; Stalker et al., 2011). The amount of time taken to build relationships and rapport with participants varied considerably with some researchers investing time prior to data collection (Nonnemacher & Bambara, 2011; Stalker et al., 2011), whereas others invested time at the start of the research process and continued to build rapport throughout the data collection process (Bernert & Ogletree, 2013; Ellem & Wilson, 2010; Gates & Waight, 2007; Stalker et al., 2011).

Considering the role of relationships

Although not frequently discussed, some researchers highlighted the need to consider the role that pre-existing relationships (e.g., among: participants, participants and researchers, or participants and paid support staff) may play in influencing the behaviour and responses of participants who may provide responses they feel will please relevant parties (Gates & Waight, 2007; Llewellyn, 2009). To manage these processes, several focus group based studies established ‘new’ groups among people who did not know one another in order to minimise the reproduction of ‘learned’ responses (Butler et al., 2012).

Data analysis processes

Engaging participants in data analysis through the process of member checking was a key inclusive research practice used by a small number of studies. This process was usually conducted through a focus group at the end of the data collection and analysis period (Beart, Hardy, & Buchan, 2004; Frawley & Bigby, 2011; Hillman et al., 2012). Member checking sometimes also involved researchers sending participants transcripts or summaries of the findings for feedback, although these processes rarely resulted in changes to the results (Furness et al., 2011; McClelland et al., 2012; Tuffrey-Wijne, 2013; Young & Chesson, 2008).

Closing the research loop

Only a few researchers drew attention to the responsibilities associated with working closely with a vulnerable, socially excluded population, which highlighted the difficulties associated with withdrawing from participants once the research was completed (Atkinson, 2005). Strategies’ used to address these concerns included producing findings and reports in a format that was accessible to all participants (Manning, 2010; Stevenson, 2014). For example, one photovoice study provided participants with a scrapbook of their photos (Jurkowski, 2008) and a second displayed participants’ photos in an exhibition (Povee, Bishop, & Roberts, 2014).

Use of advisory teams or researchers with intellectual disability in the research process.

In a minority of studies, researchers with intellectual disability were engaged as advisors, generally through research advisory boards (e.g., García Iriarte, O'Brien, & Chadwick, 2014; McClimens, Partridge, & Sexton, 2014; Tuffrey-Wijne et al., 2013), or in paid positions as researchers engaged in research processes (e.g., during the formulation of research questions, data collection as interviewers or focus group facilitators, data analysis and dissemination of findings) (e.g., Brown, Dodd, & Vetere, 2010; Butler et al., 2012; García Iriarte et al., 2014; Koenig, 2012; McDonald, 2012; Miller, Cooper, Cook, & Petch, 2008; O'Brien & Rose, 2010). Advisors or researchers with intellectual disability were often engaged in piloting data collection tools (e.g., interview schedule, focus group questions) and subsequent modification of the tool prior to data collection (e.g., Arvidsson & Jonsson, 2006; Banks, Jahoda, Dagnan, Kemp, & Williams, 2010; McDermott & Edwards, 2012). Commenting on the strength of this, Butler et al. (2012) found participants appeared more open and comfortable with researchers with intellectual disability who facilitated focus groups.

Discussion

To my knowledge, this is the first review to synthesise qualitative research methods used with people with intellectual disability to identify good practice research that embodies the principles of inclusive research with this population group. Findings suggest a relative paucity of research implementing a suite of practices to include people with intellectual disability: a majority of studies were limited in their use of research practices that included participants with intellectual disability and applied only small changes (e.g., modified consent forms with plain English and pictures). Most of the practices identified in this review were reactionary and problem-solving focused; researchers rarely applied research practices throughout the entire research process (e.g., across study design, implementation, analysis and dissemination).

Across the review, a small handful of studies were innovative and embodied an inclusive research approach. While the majority rarely reflected explicitly on their role in the research process, those who did called for more discussion on the reflective processes required to work with people with intellectual disability (Ellem, Wilson, Chui, & Knox, 2008). Those who worked with people with intellectual disability as members of the research team or advisory team reflected on the benefits this had on their research and data collection. Benefits included acknowledgement of the different skills people brought to the team, particularly in relation to helping participants share their stories and being able to ground interpretations within lived experiences (Butler et al., 2012; Haigh et al., 2013; Koenig, 2012).

Although not a focus of this review, the absence of a detailed discussion of data analysis processes was notable across the included studies. Only a handful provided a detailed description of their data analysis process or highlighted the challenges they faced during data analysis: working with limited data (short responses, often single worded), concerns of over analysing data and replacing the voice of participants with their own and being able to present the data with supporting ‘nice’ quotes (i.e., quotes longer than a few words) (Burton & Walters, 2013; Findlay, Williams, & Scior, 2014; Lafferty et al., 2013; Mahy et al., 2010; Perry et al., 2014). In looking to the literature for guidance there is limited open discussion of this issue (Stevenson, 2014). This may be due to the type of journals the articles were published in; a large majority of the studies were published in intellectual disability specific journals. These journals tend to print only a small number of qualitative articles and may not be versed in reviewing this type of research (see Beail & Williams, 2014). An open discussion is needed to build upon our understanding as researchers when working with challenging data to prevent researchers reinventing the wheel.

Despite many studies only making small changes in their research practices, the review did identify the many and varied practices that researchers took to include participants with intellectual disability. Drawing from these findings, I have developed a blueprint of inclusive research practices that qualitative researchers can use as a starting point when incorporating inclusive research principles in their research. The blueprint presents research practices grouped by phases across the research process: setting the research agenda, planning and preparation, collecting the data, data analysis and spreading the word. The aim of the blueprint is to improve researcher’s ability to be inclusive of people with intellectual disability as participants of research. Table 4.2 provides a detailed description of the research practices that can be implemented at each phase of research.

Table 4.2 Blueprint of research practices to include participants with intellectual disability in qualitative research.

Research practice	**Explanation of research practice**
Setting the research agenda	
Consider using an inclusive research approach	• Research agenda should be set by people with intellectual disability or if not possible, involve people with intellectual disability as early on in the research process as possible. • If the area of research is already set, consider a research advisory group that includes people with intellectual disability to guide the research and researchers with intellectual disability to be involved in other research processes (i.e. data collection, data analysis). • Be clear in research documentation about the degree of involvement in the research process by people with intellectual disability but, also, be flexible if the level of involvement was to change.
Planning and preparation	
Pilot the data collection tool	• Pilot the data collection tool with people with intellectual disability to ensure the data collection process is appropriate and to determine if there are any difficulties with words, phrases or questions.
Build relationships and rapport	• Researchers should consider if they will devote time to building relationships and rapport with participants and how they will achieve this. Some literature suggests building relationships and rapport with participants to be unnecessary in some situations (Morse, 2015), however, it can be argued that for this population group this is an important process.
Allow for additional time	• Researchers should be conscious of the additional time which may be required to access potential participants through gate-keepers, explaining the research to potential participants and their family or carer (where necessary) and gaining informed consent.
Where appropriate accommodate support people and gate-keepers	• Researcher should be conscious of accommodating support people and gate-keepers throughout the research process as they can be important to supporting the research process.
Prepare for a diverse range of communication	• Researchers should prepare with alternative questions or ways of asking information from their participants as well as develop a range of strategies to support a diverse range of communication to ensure they are best prepared to communicate with their participants.

Plan for withdrawing from participants	• Researchers should plan early on the way they will withdraw from participants; this is particularly important if the researcher has built relationships and rapport with participants over a period of time.
Collecting the data	
Consider external factors related to participation and data collection	• Consideration should be given to the busy lives participants live and the difficulties that may arise in organising appropriate times and places to meet and conduct the research. • Researchers should consider where they meet with participants as transport options may be restricted by paid support staff availability or the participant may be anxious to travel to somewhere new or find the new venue distracting. • Researchers should be aware of meeting in a place that, for the participant, may have pre-set rules or behaviours.
Get the timing and pace right	• Researchers should consider the timing and pace of data collection and ensure it is appropriate for each individual participant. • Where possible, spreading data collection over multiple sessions to give participants the opportunity to go home, reflect and formulate their responses.
Consider the role of relationships	• Researchers should be aware of the relationships between parties involved in the research (i.e. participants, family members, paid support staff and the researchers) and if this may affect the data collection.
Focus the research on participants	• Throughout the research process, the focus of the research should be on the participants with intellectual disability while being accommodating of the support people and gate-keepers involved.
Data analysis	
Where possible include people with intellectual disability in data analysis process	• Decisions about the involvement of people with intellectual disability in the data analysis should be made.
Spreading the word	
Produce outcomes accessible for participants	• Researchers should produce outcomes that are accessible to participants.
Where possible include people with intellectual disability in the dissemination of research findings	• People with intellectual disability should be involved in the dissemination of research through authoring articles and presenting results at conferences or community meetings.

The blueprint is intended to inform and extend current research to ensure more researchers draw on inclusive research practices, with the longer term goal being an expansion of the adoption of the key principles of inclusive research in the intellectual disability field. Embodying inclusive research and its approaches and practices is a difficult and complex process. Moreover, as Walmsley and Johnson (2003) note, conducting rigorous research that is useful to people with intellectual disability is particularly challenging, but by working towards research that is rigorous and engaging with people with intellectual disability as both participants and researchers we are more likely to produce high quality research that is generalizable for people with intellectual disability and can be used as evidence to support change (Walmsley & Johnson, 2003).

Limitations of review

The findings of this review should be interpreted in the context of a number of limitations. This review used rigorous, systematic search strategies and articles were independently reviewed. However, the review was not led by an advisory team of people with intellectual disability and article selection, data extraction and analysis was done by one researcher. Given the large scope of the study, the initial list of articles was briefly reviewed and it is possible that not all potentially eligible qualitative articles were located. Due to the large number of articles, study authors were not contacted for more information. Further, grey literature was excluded and only English language articles were reviewed; however despite these limitations the broad number and range of papers included will no doubt have ensured the study findings are based on saturation of the data (Pope, Ziebland, & Mays, 2000).

4.3 Conclusion

By applying the inclusive research practices identified in the blueprint and, if possible, embodying an inclusive approach, researchers have the potential to improve the standard of research being produced in conjunction with people with intellectual disability. Inclusive approaches to research can create the opportunity to work with people with intellectual disability to produce research that is meaningful and useful to them while progressing and expanding the use of the social model of disability when working with people with intellectual disability.

More rigorous qualitative research that embodies the principles of inclusive research with people with intellectual disability is needed and the need for researchers to be transparent about the practices they employ is clear. The inclusive research practices form a blueprint from which to expand the current use of practices to engage with people with intellectual disability. This is a complex task and it will be difficult to incorporate all of the inclusive research practices identified in this review when conducting research; researchers should strive to meet in the middle and be as inclusive as possible of people with intellectual disability. This process will take time to achieve, but small steps are valuable. It will contribute to the development of a body of literature that reflects and builds on an understanding of what works when conducting qualitative research with people with intellectual disability when embodying the key principles of inclusive research.

Overall, this chapter introduced and provided a foundational understanding of the guiding methodological framework of this research, inclusive research. The key principles of inclusive research were used to guide a systematic mapping of the literature and develop a blueprint of research practices that can be used as a starting point to include people with intellectual disability as participants in qualitative research. This blueprint will be used to guide and inform the research practices used in this thesis to be inclusive of people with intellectual disability as participants. This blueprint also contributes to the thesis aim of identifying good practice when conducting qualitative research with people with intellectual disability. Moving forward, the following chapter will describe the methods, informed by an inclusive research approach and inclusive research practices that were used in this research.

Chapter 5 Methods

This thesis draws on multiple qualitative research methods to investigate the role social support plays in facilitating health practices, such as physical activity among people with intellectual disability. As Chapter 4 outlined, my aim was to conduct research that embodied the principles of inclusive research. To achieve this, I incorporated an advisory approach and applied a comprehensive array of inclusive research practices, in accordance with those outlined in the blueprint developed from the systematic examination of the empirical literature. In taking this approach my research sought to acknowledge and value the contributions people with intellectual disability make to research as both researchers and participants.

The following chapter provides a comprehensive account of the methods used to answer the central research question of this thesis: *What role does social support play in the health practices of people with intellectual disability, specifically in relation to their engagement in physical activity?* In addressing this question, the thesis aimed:

- To develop an understanding of social support for people with intellectual disability;
- To develop an understanding of the role social support plays in health practices, such as physical activity, for people with intellectual disability.

Stepping through the methods, the chapter is presented in seven sections. The first indicates the ethics related to this research. The next section then examines the inclusive approach adopted for this thesis and the processes used to engage a person with intellectual disability as a research advisor. The chapter then provides an overview of the multiple methods used and the basis for their inclusion in a study engaging people with intellectual disability followed by a discussion of the research journal. Sections four and five discuss the processes of recruitment considers the methods I adopted to work with family and paid support staff. Section six details the data collection processes and maps the sequence of interactions with participants, beginning with establishing consent through to interviews, participant observation, photovoice and the final interview. In the final section I discuss the processes of data analysis and consider the strategies I adopted to develop ‘thick analysis’. Throughout this chapter I have also endeavoured to discuss and signpost, using italicised text, the inclusive research practices I applied through this research to ensure participants were actively engaged. A description of each of the inclusive practices used is also summarised in Table 5.1.

Table 5.1 Summary of use of research practices identified in blueprint.

Research practice	**Description of research practice employed in research**
Setting research agenda	
*Consider using an inclusive research approach	An advisory approach was used to guide the research. A research advisor was recruited in the preliminary stage of the study to provide advice on the research and research processes.
Planning and preparation	
Pilot the data collection tool	During research advisor meetings the methods for data collection were piloted with the research advisor. This process often resulted in small, but important, changes to the planned approach. Mock data collection (e.g., developing a concept map of social support) was practiced with the research advisor and proved a valuable experience.
*Build relationships and rapport	The design of the research lent itself to building rapport with participant. I spent time before and after meetings asking questions and talking with participants to build rapport.
*Allow for additional time	Additional time was allowed to identify, recruit and collect the data from participants. It was planned to allow additional time to gain informed consent but this was not always utilised.
*Where appropriate accommodate support people and gate-keepers	Support people, where applicable, were kept informed throughout the research.
*Prepare for diverse range of communication	A list of questions and/or topics was prepared and these questions were discussed with the research advisor who assisted in developing alternative questions and prompt and probes. We also discussed alternative ways of approaching topics. This approach to interviewing allowed for me to work out how to effectively communicate with participants.
*Plan for withdrawing from participants	I attempted to prepare participants for the end of the research when I would be disengaging with participants. However, this was not always successful.
Collecting the data	
Consider external factors related to	Meetings with participants were made at a time and place convenient for the participant and I tried to meet somewhere quiet and private. I was aware of the influence of different environments had on my meetings with participants, this influenced both myself and the participant. I regularly met with one

participation and data collection	participant in a large shopping centre food court. Each meeting we tried somewhere different to meet, at the time I did not think the environment played a large role for the participant. However, for me it increased my troubles with hearing her as she was softly spoken. Towards the end of the research process, her timetable changed and we were able to meet at her house. I am unsure if being able to hear each other more clearly, the change in the environment or having built rapport with her was the reason I felt we were able to better communicate. For other participants, I generally met with them at their home. At times, I felt that participants may have been following the 'rules' of their home environment. Sometimes the home environment was distracting (planes flying overhead, staff popping in to get something).
*Get the timing and pace right	I attempted to ensure the pace of data collection was appropriate for each individual participant.
Consider the role of relationships	I regularly met with most participants on their own; for some they had a support person who was available (in another room) whom we could call upon if necessary. Two participants had a support person (their mother) attend our meetings. One support person aided in communication with the participant and was able to elaborate on his answers. The other support person sat in to support the participant, as she was shy and nervous about meeting with me. Occasionally, a support person would be present at our meetings as they were around at the time I was there. At times, I felt the presence of a support person may have affected what participants shared with me, however, in most instances I was able to revisit the topic at another time when they were not present.
*Focus the research on participants	I endeavoured to keep research focused on participants. This sometimes required redirecting the conversation to the participant when a support person dominated the discussion.
Data analysis	
Involve people with intellectual disability in the data analysis where possible	From the outset I had intended to ask the research advisor to be part of the analytical process, however, due to the additional time it took to begin data analysis this was not possible within the timeframe.
Spreading the word	
Produce outcomes accessible for participants	I aim to produce information regarding the findings of this research that is accessible for participants and other people with intellectual disability. The research advisor will be consulted to ensure this is accessible.

Where possible include people with intellectual disability in the dissemination of research findings	I would like to involve the research advisor in the dissemination of the research. She is well experienced at public speaking and involving her in presentations about the research may be an option she is interested in. Additionally, the research advisor and I are involved in a collaborative paper about inclusive research.
* Indicates research practice is discussed in detail in text.	

5.1 Ethical considerations

Many significant ethical issues must be considered when conducting research with people with intellectual disability. Ethical approval for the research was received from the University of Queensland’s Behavioural and Social Sciences Ethical Review Committee (#2012000460; Appendix A). To augment the information provided in the ethics application, I have endeavoured to draw attention to the key ethical considerations for this study throughout this chapter.

5.2 An inclusive approach: Engaging people with intellectual disability in an advisory capacity

As the previous chapter outlined, the involvement of people with intellectual disability in research in an *advisory capacity* is an inclusive approach intended to facilitate engagement and obtain advice on key research decisions including: design, recruitment, data collection and analysis (Bigby et al., 2014; Walmsley & Johnson, 2003). For the purposes of this research, an advisor was engaged to provide guidance on the research plan, methods, interview schedules and materials for participants to improve the relevance, quality and accessibility of the research for people with intellectual disability (Bigby et al., 2014; Walmsley & Johnson, 2003). Although only one step above a tokenistic approach on inclusive research spectrum, the advisory approach was considered best suited to the practicalities of this research. Approaches higher along the spectrum required time and financial investments (e.g., the person with intellectual disability should be employed in the research team) beyond the capacity of a doctoral study. However, in adopting the advisory approach, I was actively aware of its limitations, particularly in relation to the tendency of researchers to engage advisors in a limited capacity (Walmsley & Johnson, 2003). To address this, I actively worked with my advisor to ensure input and guidance was sought at all stages of the study.

In recruiting individuals to the research advisory group, I sought to engage people with intellectual disability who were aged 18 years or older. Recruitment methods included an email advertisement through the extensive contacts of an intellectual disability centre involved in providing clinical, education and research services, and personal invitations to individuals who had previously worked with the intellectual disability centre in a similar role. Two people registered interest; however due to extensive commitments one of the candidates was unable to be involved. The remaining candidate was a young woman in her early 30s who identified as a person with Down syndrome. The candidate used public transport independently and was able to read, write and communicate verbally. She lived in a self-contained unit in her parents’ home, worked part-time in administration and was actively involved in teaching at a local university. The candidate also had previous research experience, including providing feedback on research materials, and was actively involved in disability organisations and non-disability organisations that focused on physical activity and social activities.

The intention had been to engage a small team of advisors in the research; however, given the limited number of individuals who expressed interest and the need to adhere to the research timetable, the possibility of including only one person on the advisory group was discussed with the candidate who indicated she was confident acting as a sole advisor. The research advisor could be described as a ‘usual suspect’ (Frawley & Bigby, 2011) given her previous involvement in research activities. However, her experience increased my confidence that she could work as a sole advisor and also ensured she was quickly able to adapt to the limited research timeframes of the thesis. The rapport we had established through previous activities also enabled us to have open and honest discussions.

Once recruitment to the research advisory role was complete the advisor was engaged in providing feedback on research materials, information sheets, consent forms, recruitment and data collection instruments and processes. In accordance with Walmsley and Johnson (2003) and Bigby et al. (2014) I was conscious that engagement with my advisor needed to be active and genuine to ensure her views were appropriately acknowledged and considered. To facilitate this, we worked together to develop a Terms of Reference for the advisory team (see Appendix C) and held regular, face-to-face meetings with her throughout data collection. When I had many items to discuss or documents for the advisor to read I emailed the document/s and a meeting agenda a week before our meeting, allowing her time to consider the topics and read the documents. Meeting agendas included: reviewing research materials (e.g., consent forms, information sheets), practicing asking questions and mock data collection processes, building rapport with participants, reflecting on experiences and thinking about how to close the loop with research participants. In total, nine meetings were held. The research advisor provided valuable input into the research processes and ensured the processes met the needs of the research participants. She provided extensive input into the materials provided to participants; this resulted in additional information and clearer writing, particularly in relation to the photovoice component. Other key contributions included: the opportunity to carry out mock interviews and clarify key components of the research, devising strategies to facilitate discussions with participants about social support, and managing support people who dominated conversations. The feedback and discussions in these meetings was invaluable and resulted in clearer questions and explanations of the concepts of the research. This process also built my confidence in explaining the research to people with intellectual disability.

5.3 Research Methods

The study drew on multiple qualitative methods to engage with participants about their understandings and experiences of social support and their corresponding involvement in physical activity. The methods used included: in-depth interviews, participant observation, photovoice and a research journal. **In-depth interviewing** involves a guided conversation with participants to seek their perspectives and experiences (Liamputtong, 2013) and has been identified as an important method when conducting research with people with intellectual disability because it allows participants to discuss experiences in their own words. Importantly, this conversation also allows researchers to adapt and adjust their communication to meet the needs of participants (Finlay & Lyons, 2001).

Participant observation was the second method drawn on to gather data for this study. Participant observation involves a researcher observing events in the participant's natural context and is appropriate when little is known about the area of interest (McKechnie, 2008). The role of the researcher can range from being a complete observer to engaging in the activity with the participant (McKechnie, 2008). Participant observation can be used over long periods of time and data is recorded in field notes (McKechnie, 2008).

The third method used in this research was **photovoice**. Photovoice involves participants taking photos, related to the research topic, and sharing them with the researcher to promote discussion (Wang & Burris, 1997). Photovoice seeks to actively engage participants and provides an avenue for expression that extends beyond words (Jurkowski, 2008). Photovoice has not been used extensively with people with intellectual disability (Jurkowski, 2008); however, Povee et al. (2014) suggest it may be an empowering experience for participants with intellectual disability as it support different communication styles and allows people to represent their experiences through different mediums. Traditionally, photovoice involves a group activity where participants learn about the method, take photographs and share them in a group discussion (Wang & Burris, 1997); however, Booth and Booth (2003) suggest discussing the photos individually may better suit the needs of some people with intellectual disability. The current study adopted this suggestion and worked with the individuals who participated in this method.

From the outset of the research I attempted to keep a **research journal** recording research decisions, including research advisor meetings, and reflections on my thought processes and participation in the research. However, I frequently I struggled to write reflectively and found the process of audio recording my thoughts after contact with participants and later transcribing them helpful.

The multiple methods used in the study were implemented over numerous sessions held across a 10-month period in 2015. The use of multiple contact points is strongly recommended for research with people with intellectual disability because it can enhance communication (e.g., Bernert & Ogletree, 2013; Forbat & Wilkinson, 2008; Hillman et al., 2012) and facilitate a richer and deeper conversation with the participants (Liamputtong, 2013). By spreading the data collection over a longer period, I was also able to engage with participants when they started new activities or completed an activity (e.g., finished swimming for the season), and it facilitated *building relationships and rapport.* The need to build rapport with participants has been the focus of much debate in the literature with some arguing rapport is built during the recruitment, consent process and initial meeting, so a formal strategy for researchers and participants to ‘get to know’ each other is unnecessary (Morse, 2015); however, McDonald (2012) argues this perspective may not reflect the needs or wishes of people with intellectual disability.

5.4 Recruitment

I aimed to recruit participants aged 18 and over who had lived experience of intellectual disability. There was no minimum requirement regarding participants’ physical activity or experiences of social support. Ethic committees frequently encourage the use of support people to recruit people with intellectual disability as they believe it reduces the risk of coercion (McDonald & Kidney, 2012); however, this can also lead to bias in recruitment (e.g., the support person identifies those they think will be most appropriate rather than providing opportunities to a range of people). In an effort to minimise potential recruitment bias and make direct contact with individuals with intellectual disability, I used multiple recruitment strategies including email invitations sent via mailing lists held by an intellectual disability centre involved in providing clinical, education and research services, a local Down’s syndrome organisation, and a large intellectual disability sporting organisation. Following this process, five family members, having received an email as a ‘gate-keeper’, indicated that their relative had expressed interest in participating in the research and a staff member from a service organisation spoke with two members about possible participation. Three additional expressions of interest were received but were not included in the final sample as one person was under 18 and two people elected not to participate. Overall, seven participants were recruited to participate in the study and were engaged in multiple in-depth interviews. Four participants agreed to be involved in participant observation and six participated in photovoice. Table 5.2 details the contact points and methods used with each of the participants, pseudonyms have been used.

Table 5.2 Research contact with participants.

Participant	Research contact and setting
Barry	• Six interviews at Barry’s house • Photovoice
Mark	• Nine interviews at Mark’s house • Photovoice • One participant observation ○ Walk around neighbourhood together
Phoebe	• 10 interviews at coffee shop convenient for Phoebe and Phoebe’s house • Photovoice • Three participant observations ○ Exercise class ○ Practising team sport in park ○ Tour of gym
Hayley	• Two interviews at Hayley’s house • Photovoice • Three participant observations ○ Swimming competition ○ 2 team sport competitions
Daisy	• Two interviews at Daisy’s house with her mother present
Matthew	• 12 interviews at Matthew’s house • Photovoice • One participant observation ○ Walk/run together around local neighbourhood with his mother
Greg	• Two interviews with mother present at coffee shop convenient for Greg and Greg’s house • Photovoice

5.5 Working with family and paid support staff

The research processes also involved active engagement with families and support staff. I endeavoured to *accommodate support people* (parents, siblings and paid support staff) by fostering and maintaining an open relationship throughout the study. This was pertinent as key individuals played a role in gate-keeping during recruitment, as previously discussed (e.g., they were responsible for initiating discussions with participants about being involved and contacted me to register interest on behalf of the participant), and for supporting participants throughout data collection. To support these processes, I regularly liaised with families/support staff to explain the purpose of the research, clarify what participation would involve, and provided them with written information about the study (e.g., information sheets for support people, see Appendix D).

The importance of keeping families and support stuff informed was reinforced during the early stages of the study when I became aware that the service organisation supporting two of the participants did not fully understand the purpose of the research (i.e., the support person had thought the study was seeking to implement strategies to increase individuals' participation in physical activity). To address this, I had a follow up conversation with support staff to clarify the aims of the study and discuss what participation would involve.

During data collection I worked with participants and support people to determine the level of involvement support people would have in the research. Some support people were involved in organising meeting times, others requested to be kept informed, and some left arrangements to the participants. Liaising with support staff and participants to organise data collection required flexibility due to participants' busy lives. On many occasions we experienced difficulties finding suitable times, particularly when the participant wanted to have a support person present. To support participants, I endeavoured to be very flexible and provided *additional time* for data collection, extending this phase of the research from six to 10 months. Despite this, some participants were still only able to take part in a smaller number of interviews due to their busy schedules.

Support people were at times involved in the research conversations I had with participants. However, as I wanted to *focus the research on participants* I did not seek informed consent from support people but instead always revisited topics discussed by them with participants. Where the input of support people was valuable and the content of our conversations not otherwise discussed with participants, I documented their perspectives in my research journal and used this in the analysis and presentation of results. At times, support people provided important insight into the context of participant's experiences and on reflection, they were a valuable source of information (e.g., when participants did not recall why or how they began or stopped an activity) and their consent should have been sought.

5.6 Data collection processes

Initial meeting: gaining informed consent and starting data collection

The first meeting with participants was used to discuss the research and to work through the information sheet and consent processes. In all cases a support person was present to provide assistance through the consent process. The information sheet and consent form were written in plain English and set out clearly (see Appendix E and Appendix F). These materials were reviewed by the research advisor to ensure they were easily understood, accessible and appropriate. The consent form outlined the in-depth interviews as the principle method of data collection and also included an 'opt-in' box for participants to identify if they would like to be involved in photovoice and participant observation – this reduced the need for additional consent forms and the potential for confusion. Importantly, the consent form was sent to participants prior to our initial meeting to ensure they did not feel obligated to participate in the study, and to enable them to consider also being involved in the photovoice or participant observation. Due to the additional ethical considerations involved in the photovoice, including confidentiality associated with taking photos of associates and strangers, along with ownership of the photos (Booth & Booth, 2003), it was necessary to develop an additional information sheet outlining photovoice to ensure participants and supporters were cognisant of what this method would involve (see Appendix G).

All participants were assumed to have capacity to give informed consent unless otherwise indicated to the researcher, and all participants provided their own consent. Determining capacity to consent was an ongoing process and was based on the MacArthur Competence Assessment Tool for Clinical Research (Applebaum & Grisso, 2001). I asked questions at the time of consent and used a continuous consent process across all data collection points, which included the following questions: "Do you have any questions about what I just said", "Can you tell me what you will do in this project?", "How long will your part in the project take?", "If you don't want to answer a question, do you have to?", "Is it ok to talk to you today?". Throughout the study participants were also reminded they could cease participation at any time and a withdrawal of consent form was developed (see Appendix H). Participants were also frequently reminded they did not have to answer any questions.

The consent process was intended to be an informal conversation about the research as I was conscious of not making the participants feel they were being tested or that I did not think they had the capacity to participate. I endeavoured to allow *additional time* for participants to reflect on their involvement in the research before signing the consent form, but the majority had already done this with another person (usually the person who contacted me about the research) prior to our initial meeting. The two participants supported by an organisation chose to go through this information at a later time with the support of a paid worker.

First interview

The first interview usually occurred on the same day that consent was provided. In most cases support people left following completion of the consent process; however, two participants had a support person present at all interviews. The majority of interviews took place in the person's home or in a local coffee shop. All but one participant consented to interviews being audio recorded, in this instance notes were taken during the interview and written up immediately after.

To continue to build my relationship with participants following the initial meeting, I used an ice-breaking tool that provided information about myself (e.g., my likes, dislikes, hobbies) at the first interview. The tool also included prompts for participants to talk about these topics in relation to themselves to help generate conversation (see Appendix I). Relationships and rapport were also developed through informal conversations before and after meetings (e.g., asked about their day, about their family/friends). I met some participants at morning or afternoon tea and we would have a drink or something to eat together which also helped to stimulate discussions.

The interviews discussed a broad range of questions to explore what participant's did each week, what physical activities they generally participated in and what they had done since the previous interview, who were their social networks and supports, what support they received to be active, their social connections, and any barriers or facilitators they may have experienced in being active. Questions included: "Can you tell me more about [activity]?", "Can you tell me what a friend means to you?", and "Can you tell me about how you get to [activity]?". There was not a set question order or timeframe and the *pace of conversations was appropriate* for each participant.

To *accommodate the different communication styles* between myself and participants I aimed to ask clear questions and allowed additional time for participants to respond. If they did not respond (or it was clear from non-verbal communication they were unsure of what I was asking) I rephrased questions. I also discussed with my research advisor other ways of asking questions about topics I was having trouble prompting participants to talk about and was able to practice these questions with her. No individual was excluded on the basis of their communication ability. One participant primarily communicated with gestures or typing on an iPod, and his communication was elaborated on by his mother. I found the speech of another participant difficult to understand but over time it became easier to comprehend what he was saying.

Subsequent in-depth interviews

Interviews were conducted at multiple time points to allow flexibility in our discussions and for us to return to topics. This also allowed time to build relationships and rapport with participants facilitating a natural conversation about the topic with minimal prompting from me. For each subsequent interview, I developed two to three questions to start off conversations if one did not start naturally. This also helped to ensure I covered topics or further explored topics we had talked about previously. The questions were used more often with those participants who were less talkative than others.

Interviews with most participants occurred approximately every two to three weeks over a 10-month period. Sometimes longer gaps occurred due to participants' holidays or other activities. Some participants had more interviews than others for a range of reasons including; they wanted to talk more about a particular topic, it took longer to cover the topics, or because they (and their support person) had more time to continue interviews.

Participant observation

Participant observation was interspersed across the data collection period. Participant observation was used to observe and experience the participants' process of being active and any support they received. It was also used to observe and experience the physical activity participants took part in and the context within which it occurred. This was particularly important as I have limited experience of different physical activities and potentially different experiences of the environment in which physical activity occurs.

Participants were able to opt-in to the participation observation component of the research; four participants opted-in and there were eight observations in total. I went on walks with participants (one participant ran while his mother and I walked), attended exercise classes, swimming carnivals, team sport competitions, playing a team sport with participant and was given a tour of a participant's gym. I asked questions during or after the activity (depending on the activity and participant) about what the person liked about the activity and the factors that facilitated or impeded participation. Meetings were generally arranged with the participant with occasional input from support people (e.g., directions, best time to come, and liaison with people running the physical activity). I generally met with participants before the start of the activity; participants then determined the extent of my involvement in the activity. Often my role was restricted to observation if it was a class or group based activity or competition (e.g., exercise class, swimming). Participants also invited me to participate in an activity with them (e.g., walking, playing a sport). The process of participant observation provided an additional avenue for building rapport with participants and their support people.

Photovoice

Six participants engaged in photovoice activities, to varying degrees. Participants were asked to take photos related to their involvement in physical activity and of things that might have helped or hindered them from being active. Participants received an additional information sheet regarding photovoice, which was discussed with them and their support person (if present) well in advance so there was sufficient time for the participant to review the information and ask questions (see Appendix G). The information sheet discussed when it is and is not appropriate to take photos, what to do when taking a photo of another person and what happens to the photographs after they had taken them.

All participants had access to digital cameras or smart phones. Due to a technical issue (compatibility of phone and laptop) I was unable to receive copies of one participant's photos and they were lost. For some participants, photos were taken by their support person and as a result it was often unclear who had decided to take the photo and why it was included. Three participants chose to share existing photos that related to physical activity or social support. Copies of these photos were not retained, but the discussion related to them was included in the analysis.

Once the participant had taken their photos we met to discuss them and develop captions to describe the shots (Wang & Burris, 1997); however, it was not always possible to arrange meetings quickly and as a result some of the participants could not recall the purpose of the photograph. At times, discussions of the photos were limited to a simple description of content and context, as participants did not appear interested in discussing the shots (Booth & Booth, 2003; Paiewonsky, 2011). In some cases, participants sent their photos via text message, which enabled me to engage them in a text based conversation about the photo; however, this unfortunately resulted in short descriptive responses. Despite the limitations experienced through the processes, the photos still generally provided a useful tool to prompt discussion.

In keeping with the principles of photovoice (Wang & Burris, 1997) I had intended to organise a small photo exhibit of photos taken during the project; however, due the location of some participants (i.e., those who lived some distance away), cost and limited interest from participants this did not occur. As an alternative, all participants who engaged in photovoice received a hardcopy of their photos and a photo album.

Final Interview

Having spent a considerable amount of time with participants and built a relationship I felt uneasy about concluding our research relationship and *withdrawing from participants*. Half-way though data collection I began to talk with participants about the end of the research and what that meant. I marked the final interview by focusing on summarising the information we had talked about and thanking the participant (and their support people if present) by sharing morning/afternoon tea. Despite this preparation and discussions, I found that when it came to the last meeting (or second last meeting where I indicated the next meeting would be the last) participants were confused about my departure and had not fully comprehended what the end of the research meant to our relationship. Many asked if would I be returning next year and when would they see me again.

5.7 Data analysis

Thematic analysis incorporated all data collected throughout the 10 month research process: interview data, participant observation field notes, participants' photos and my own interpretations and reflections collected in my research journal. The photos generated through photovoice and related discussions were analysed as a whole to ensure the context of the photos was captured (Paiewonsky, 2011). I triangulated data by drawing on all sources to develop a nuanced understanding of the context of participant's experiences of social support and physical activity. Key research questions were considered when analysing the data:

- What were participants' experiences of social support?
- What relationships emerged from physical activity?
- How do participants use social support to engage in physical activity?
- What was the relationship between social support and physical activity?

In answering these questions, two approaches to presenting the analysis have been used. The first, presented in Chapter 6, draws on vignettes to represent the context of participant's lives and explore their experiences of social support. The second approach, a presentation of key themes, builds on the vignettes to address the research questions relating to health practices and physical activity. The data analysis process was cyclical process; themes arising from the process of developing the vignettes where explored further in the thematic analysis and reconsidered within the context of the vignettes. The analytical method taken in each approach is discussed below followed by a discussion of the strategies used to ensure a 'thick' description of the data was possible. However, before considering the processes of analysis in more detail it is imperative that I discuss disability.

Throughout the results, consideration of participants' disability are limited to findings arising from the analysis because impairment and disability were not often discussed by participants themselves. When describing and discussing impairment and disability in the results chapters, my aim is to communicate participants' experiences of disability in such a way so as to identify the practical implications of the participant's experience of disability. The analysis is not intended to draw attention to deficits that participants may be perceived to have, rather to provide an open discussion about the context of participant experiences. I refer to individuals with intellectual disability who participated in this research as 'participants'. I have chosen not to describe them as 'participants with intellectual disability' as the focus of this research was on the individuals not their intellectual disability. Other informants are described in relation to their relationship with the participant (e.g., paid support staff member, friend, mother, etc.).

Vignettes as a tool to represent participant's context

As part of the analytical process and as a tool to represent the social context of social support and physical activity experiences of participants, vignettes were developed for each participant. Vignettes are narratives focused on describing a topic of interest (Miles & Huberman, 1994) and can be an avenue to provide a strong voice to participants

(Henderson, Holland, McGrellis, Sharpe, & Thomson, 2012). In this research, the vignettes are presented as individual summaries and then considered as a group contributing to my broader analysis of key themes (Thomson, 2007).

The vignettes were compiled based on information drawn from the multiple data sources (in-depth interviews, photovoice, participant observation and research journal) and were constructed and refined during the data analysis process (Jacobsen, 2014). Vignettes can be coproduced with participants but they are most frequently produced by researchers (Miles & Huberman, 1994). It was not possible to include participants in the analysis process given some time had passed since data collection and it would have involved a significant time commitment on behalf of the participants.

Henderson and Bigby (2017) argue, it is important to acknowledge process when writing narratives of people with intellectual disability. Although their work focuses on the development of autobiographies with people with intellectual disability, their learnings may be translated to the current context. In particular, they warn against muting the researcher's voice as this can misrepresent the analytical process and be mistaken as the voice of the individual and argue that an approach that incorporates and acknowledges the voice of both researcher and individual will most accurately reflect the processes used to develop the story. Drawing on Henderson and Bigby (2017), through the vignettes I have presented my interpretation of the narrative of participant's experiences. This is reflected in the language used throughout the vignettes and the use of quotations from participants to support my interpretations. In doing so, I have endeavoured to represent the experiences and perceptions of participants in a respectful manner.

Thematic analysis

As part of the thematic analysis I became familiar with the data by transcribing, reading, rereading and reviewing the transcripts. Through this process initial codes were developed. Further refinement of the codes continued throughout the analytical process and were grouped into categories (Vaismoradi, Turunen, & Bondas, 2013). I continually returned to the health practices, social support and physical activity literature to inform and refine my understanding. Initial analysis was led by descriptive questions (i.e., what barriers and facilitators do participants experience to being active?). Over time, these questions became more grounded and analytically focused through the recursive process of returning to the literature and to the data (Vaismoradi et al., 2013). As a tool to present the themes and sub themes, the social support framework proposed by Lunsky (2006) was used. The framework, discussed in more detail in Section 2.3, proposes there are three levels of influence on social support; individual, relationships and community. The grouping of the themes using this framework provided useful to understand the themes and sub themes across the two analytical approaches and the categories were reflective of the key notions from the health practices and social support literature.

A thick approach to data analysis

Researchers in the intellectual disability field who do not include people with intellectual disability in the analytical process often avoid over-analysing participants' data and therefore take a 'thin' approach to data analysis, relying on largely descriptive accounts (e.g., Brooker, Mutch, et al., 2015). In this analysis, a 'thick' approach where data is interpreted and analysed, was taken. Emphasis is placed on describing context to support this analytic approach as considerable time was spent with participants (Liamputtong, 2013).

Three key strategies were used to support the thick approach to data analysis including: an extended data collection process, triangulation of multiple data sources and member checking. The use of an extended data collection process provides an important opportunity to discuss a topic on a number of occasion, which can enhance the depth and quality of the information provided and clarify my understanding of participants' experiences (Marx, 2008). Triangulation of data collected using multiple methods was also used to add to the richness of the information gathered and provide a more comprehensive picture of participant's experiences (Liamputtong, 2013). Member checking, through the engagement of participants in an initial discussion of the analysis was also used to ensure 'thick' analysis was possible (Liamputtong, 2013).

Initially, member checking was done in real time to ensure I had understood what participants had discussed. After the first few contacts with some of the participants, I attempted to use a more formal tool of member checking developed by Knox, Mok, and Parmenter (2000) (see Appendix J) which involved revisiting previous discussions to determine if my interpretations were correct. The tool was reviewed by the research advisor; however, we both noted the over reliance on text. I endeavoured to use the tool in two to three interviews with three participants. The tool was generally accepted; however, it often sat forgotten on the table and was not used to its full potential. At times when I did refer to it, the tone of the conversation appeared to change as participants seemed aware that I was there 'on business'. Towards the end of the data collection, and after trying different methods for depicting social support (i.e., concept maps), it was decided to bring this information together for participants to check what they had told me. Each member checking summary was developed to meet the needs of participants (i.e., limited use of words for participants who did not read) and summarised their physical activity, social support and social activities in a visual format. As a result of this process I adapted my analysis based on feedback from participants (e.g., I had omitted activities or people) and participants were given a copy.

Overall, the process of prolonged engagement with participants coupled with the triangulation of data and member checking enhanced my confidence that I had captured participants' experiences and perceptions.

5.8 Conclusion

This chapter has provided an extensive map of the methods used in this doctoral research. Importantly, it has also considered the ways I have sought to embed the principles of inclusive research throughout this study through a consideration of the inclusive research approach used and the inclusive practices adopted. These principles of inclusive research carry through to the rest of the thesis and have guided the analysis of the data which is presented in the following chapters.

Chapter 6 Once a friend, always a friend: Understanding the context of participant's physical activity and social support through vignettes

This chapter introduces the people who participated in this study through a brief narrative examination of their lives and experiences of social support. In this first of two results chapters, seven vignettes summarise each of the participants' lives, their social networks and relationships, and the types of support they draw from these relationships. Importantly, these vignettes allow for consideration of the intersections between participants' relationships and their involvement in physical activity.

The vignettes presented in this chapter are drawn from the data (interview data, participant observation field notes, participants' photos and my research journal) collected during the 10 months of fieldwork conducted for this thesis (see Chapter 5 for a discussion of the methods used). Data were triangulated to develop a detailed description of the participants, how they spend their time (e.g., work, volunteering), their social networks and access to social support, and their involvement in physical activity. These summaries help to 'set the scene' for, and highlight key areas that require further discussion in Chapter 7. In presenting these vignettes, the chapter aims to consider the participants' experiences of social support and physical activity. Chapter 7 then extends on these findings to explore the ways in which social support is understood by people with intellectual disability and how support is used, or not, to participate in physical activity.

The quotations provided in the vignettes are reflective of the language and method of communication used by each participant. In this way, the quotations themselves communicate further detail about each participant, including their capacity and social confidence. Where necessary, I have included my questions, responses and prompts to indicate the context of the quotation. To ensure confidentiality of participants, I have not included photographs provided by participants, but describe relevant scenes in text. Pseudonyms have been used throughout this thesis.

6.1 Participants

Four males and three females aged between 21 and 59 years participated in the study (see Table 6.1). Four people lived with their parent/s, two lived in supported accommodation and one had, until recently, lived independently and was in the process of returning to independent accommodation. Six of the participants were able to verbally communicate. One participant used gestures and short responses to communicate; he also drew on his mother to elaborate his responses. None of the participants had a physical disability. Participants lived in South-East Queensland; this is a large area and consists of major cities, urban areas, coastal suburbs and rural areas. Participants were identified as having intellectual disability as they or a support person responded to recruitment material asking for participants with intellectual disability. All participants signed consent forms that identified the participant as an individual with intellectual disability; recruitment materials were distributed among intellectual disability networks including services which people needed to have a diagnosis of intellectual disability to access. I did not ask participants if they identified as having an intellectual disability/disability; however, in most cases this was something the participants brought up “because of my disability…” or by people who are in the lives of participants (family members, paid support staff at an organisation) “his disability…”.

Table 6.1 Demographic characteristics of participants.

Participant	Gender	Age	Location	Accommodation setting	Employment	Types of Physical Activity
Barry	Male	50	Urban	Supported accommodation	One day a week volunteering, open employment	• Walking • Prescribed exercises and stretches
Mark	Male	58	Urban	Supported accommodation	Three days a week, supported employment	• Walking
Phoebe	Female	29	Urban	Lives with family	Two days a week, supported employment Casual role with various shifts, open employment	• Walking • Exercise class • Personal training sessions
Hayley	Female	Mid 20s	Rural	Seeking independent accommodation	Three days a week, open employment with paid support	• Walking • Swimming • Tennis • Personal training sessions • Self-defence class
Daisy	Female	21	Urban	Lives with family	Casual role with various shifts, open employment	• Walking • Gym • Swimming • Tennis • Horse-riding
Matthew	Male	30	Urban	Lives with family	One day a week, open employment with paid support	• Walking and running • Self-defence • Golf • Gym • Swimming • Bowling

Greg	Male	22	Rural	Lives with family	Not employed	• Walking • Tennis • Swimming • Personal training sessions

Barry: independence is key

Barry is a 50 year old man who identifies as having a disability. He has lived independently in a unit that is part of a supported accommodation complex in an urban suburb for the past ten years. Many of his co-residents have also lived in the complex for many years. Barry is largely self-reliant but can draw on support workers, who live in a neighbouring flat, when needed. Barry prides himself on his ability to travel independently – he travels to work, to social engagements and to visit family and friends using public transport or walking. Barry volunteers one day a week at a not for profit organisation close to his house but is also seeking paid employment with assistance from his main support organisation.

Barry's social network is relatively large, made up in part by other residents and support workers from the organisation that provides his accommodation. The organisation fosters connections amongst its community locally, interstate and internationally and includes people with and without disabilities. Barry also maintains strong social connections with his extended family and regularly talks to his brother on the phone. Broader social interaction stems largely from his engagement in activities organised by his church (e.g., choir practice, social groups) as well as groups organised by other disability organisations (e.g., art class).

Barry engages in a number of different forms of physical activity. In particular he enjoys walking to the local community garden in his neighbourhood, which was the focus of one of his photographs. He also participates independently in exercises and stretches, prescribed by a physiotherapist, to manage muscle pain. Barry's strong sense of independence means that he has rejected offers of assistance from his support workers to do the exercises.

For Barry, unsolicited offers of help are perceived negatively and potentially disabling because they imply he is incapable. For example, Barry appeared offended when I asked if he did things with other people. In response he said he is happy with the contact he has with people and does not require additional support:

> *The things I do, I feel happy and good and happy about.*

For Barry, social support does not appear to play a direct role in physical activity, instead he draws on social connections for other social engagements. At the time of the research, Barry was seeking to engage in more social activities:

> Barry*: When I can get something I'm happy to do. I'm hoping to get into* [organisation] *next year, I'm on the waiting list. And there's a place down at* [suburb] *where I'm hoping to go and learn woodwork and I'm on the waiting list, that's full up at the moment too.*
>
> Interviewer: What kind of things do you want to do at [organisation]?
>
> B: *Whatever they can give me to do, I don't mind at all. I'm very easy going and easy to get along with I don't mind what kind of work I do.*

In summary, Barry had a relatively broad social network, much of which was formally constituted through his accommodation provider and through participation in a range of social activities that were set within a church or disability setting. Through contact with his church and employment, Barry drew on bridging relationships with people that extended beyond his immediate network. Barry's social network was not generally linked to physical activity, with the exception of the exercises for his back which were prescribed by a health care professional. His engagement in physical activity was largely connected to incidental exercise linked to transport and visits to a community garden.

Mark: "everyone's my friend"

Mark, who is in his 50s, is a friendly and social man, but also quite guarded and often cautious about sharing information about certain topics. Mark lives on his own in a unit that is part of a supported accommodation complex in an urban area. He works three days a week in supported employment and is involved with an advocacy organisation and regularly attends meetings. He is also involved in teaching activities, where he enjoys the opportunity to share his story and answer students' questions.

Mark has a large social network and busy social life and keeps a diary of his extensive social engagements. Mark regularly calls his friends to "*chat*"; he enjoys having visitors and regularly catches up with members of his support network (e.g., staying the night at a friend's house, going to the movies on the weekend). He also attends weekly dinners with others who live in the accommodation complex and attends church on Sundays.

Most of the social connections in Mark's life are long standing. The companionship and support Mark receives from friends is clearly important to him, he also receives practical support from these relationships (e.g., picking him up, driving to see friends). Mark has a broad notion of friendship, he considers "*everyone's my friend*"; as a result it was often difficult to determine whether the people Mark engaged with were paid support staff or informal supports. It was only after prompts that he reflected that you needed to know someone to be their friend:

> *I know him* [friend], *I know you very well. You know what I mean? I know you, something like that.*

In regard to physical activity, Mark participates in two regular walking activities. The first involves walking with an old friend who does not live with a disability. The time and location of the walk is organised by Mark and his companion. The second walk involves a friend with disability. This activity is organised by Mark's friend's support organisation which provides transport to the walking venue. In his photographs, Mark captured the warm-up stretches he did before going on a walk with one of his friends (having asked his friend to take the photographs).

Mark's engagement in physical activity stems from advice received from his doctor about the need to lose weight. To assist this process, Mark's friends decided to become involved to help motivate him to be more active. Mark's friends each organised a photo of themselves being active or a video offering encouragement and emotional support to prompt him to start walking again. This group effort was facilitated by someone Mark describes as a friend but who is also in a paid position to support Mark. Mark shared these photos and videos with me proudly explaining that: "*my friends did that*".

Mark enjoys the social aspect of walking with his friends, but he generally walks at a fast pace ahead of his friends which means they are unable to talk with each other while walking. This may be because Mark recognises the importance of getting the walking done at a health benefiting pace:

> *I like walking, good for my heart. I like walking all the time. Keeps me, keeps my heart beating. Good heart.*

However, Mark and his friends often finish their walk in a café, so they can enjoy coffee and a chat:

> *Walk first and then chat in the morning.*

Overall, Mark has an extensive social network, which like Barry, includes many individuals who also play formal support roles in his life. Similar to Barry, Mark experienced bridging relationships through his connection with church which provided opportunities to connect with a broader and more diverse network of individuals. The setting for these social connections occurred within a disability setting, at Mark's house and, to a lesser extent, within the wider community. Mark received a great deal of positive emotional and practical support from his formal and informal networks to motivate and facilitate his engagement in the physical activity prescribed by his health care professional. The blurring of boundaries across informal and formal supports was evident in Mark's relationships and his understanding of what constitutes a friend: for Mark friendly interactions were frequently interpreted as friendships. However, Mark's relationships were not all one-directional, as was evident when considering the reciprocal interactions that took place with his regular walking partners.

Phoebe: seeking independence

Phoebe is 29 and lives with her family in an urban area. Phoebe has two paid positions; a casual job in retail and a role in a supported workplace. Phoebe felt it important to share that she had "*a disorder, it's called OCD* [obsessive compulsory disorder]". Unlike many of the participants in the study, Phoebe did not receive daily support from a disability organisation, but she is actively involved with organisations that organise activities for people with disabilities (e.g., exercise classes).

As part of Phoebe's involvement with a disability organisation focused on providing social support she attends many social events including camps and dinners. She also engages with another organisation that run social activities every weekend (e.g., group outings to bowling, local attractions and the movies). These activities are designed to facilitate and build social support and networks for people with disability – many of Phoebe's friends, acquaintances and the people she works with attend these activities.

In addition to active engagement in social activities, Phoebe participates in a range of physical activities, including sporting competitions, weekly exercise classes and personal trainer sessions at a gym that she walks to. In a photograph she provided, Phoebe is standing in her bedroom smiling proudly next to her display of sporting medals. Around 30 medals are hung on a wall display.

Phoebe's exercise classes were organised for people with disability, she had previously attended mainstream classes but the regular rotation of students caused too many disruptions for her. Phoebe also played a team sport, but at the time of the interviews was taking a break to focus on her mental health.

Phoebe's involvement in social and physical activities was generally facilitated and organised by her parents, though this clearly created some tensions as Phoebe perceived that she had limited control over decisions about her life:

> *I don’t know if I live my own life really. Sometimes my parents run my own life. Sorry I just want to do my own choices in life.*

For Phoebe, the decision to stop her team sport was driven by her family, although she acknowledged that taking time out was needed to manage her OCD:

> *Yes, just for a little bit. Just to clear my head … focus on my OCD and get better and return to [team sport].*

However, the team sport had been a key setting through which Phoebe saw some of her friends and she missed those connections. Despite the lack of contact, Phoebe understood that friendships were everlasting; once you make a friend, you stay friends. Role models were also important to Phoebe, she looked up to her role models including past exercise teachers, prominent sporting personalities and ambassadors for her disability organisation. In another photograph provided by Phoebe, she is standing next to her wardrobe where she has hung posters and pictures of friends and role models, including a prominent sporting identity who supports people with disability in sports.

Overall, Phoebe is an active young woman with a large and diverse social network drawn from her involvement in local disability organisations, her two workplaces and her family. Phoebe experienced mostly positive social support from her social network but she also drew attention to her experience of negative social support. Phoebe’s reliance on formal supports was limited to her employment arrangements and her participation in social and physical activities organised by disability based organisations. These formal supports often provided an avenue for Phoebe to see her friends who, during physical activity, provided emotional and companionship support. Whilst Phoebe had connections outside of a disability setting, she almost exclusively saw her friends within a disability setting. In addition, many of Phoebe’s friends and ties from one activity overlapped with networks participating in other activities. As a result, Phoebe experienced a strong sense of connection through the disability community.

Hayley: utilising formal support to promote independence

Hayley is a socially active young woman who lives more than 100 kilometres from Brisbane in a rural area. Hayley lives independently and receives support consistently from the same two support workers who provide assistance with transport and household tasks including cooking and cleaning. At the time of the interviews, Hayley was looking for permanent independent accommodation. Hayley works three mornings a week in a retail role with support. Hayley experiences high levels independence over her decisions and her activities.

Hayley has strong family connections, she often commutes to work with her mother and visits her grandmother, who lives nearby, regularly. She has a positive and supportive relationship with her father and speaks to and sees him regularly. Hayley also has a dog who she is devoted to and walks by herself, with her mother or one of the support workers at least once a day. Hayley has many friends but many live far away and the only way to travel to their place is by car. Because of this they sometimes slept at one another's houses.

Hayley's family has a strong ethos related to health. Hayley's mother works in a health profession and her father has strong views on staying healthy, irrespective of disability. For example, during a participant observation session, Hayley's father was supporting Hayley at a sporting competition I was observing. He spoke to me while Hayley was competing and shared his thoughts on Hayley's physical activity; Hayley's father was worried she did not push herself enough (e.g., run fast enough) to get the full health benefits from her physical activity.

Hayley engages with many formal supports and these are often key to supporting her independence. In addition to the support workers who support her at work and at home, Hayley attends a day service run by a local disability organisation on the days she does not work. At the day service, Hayley undertakes a variety of activities including shopping and learning life skills (e.g., cooking, being safe when out). Another local disability organisation also organises social events, such as discos, throughout the year which she attends with her friends.

Hayley is involved in a range of physical activities, primarily in the afternoons throughout the week, and on the weekends. Transport and support for these activities is primarily provided by formal supports or her family. Hayley has built close relationships with her two support workers. She often took photos of the support workers or people who supported her to demonstrate the practical support she receives from them to be able to participate in the activities she does. In one photograph she took, Hayley is standing with her personal trainer and support worker at the gym. They are standing with their arms around Hayley, smiling, surrounded by gym equipment and people working out in the background.

Hayley was frequently involved in competitions for her chosen sporting activities. For some competitions she needs to travel and this is supported through informal supports; her family and her friend's family take turns to drive Hayley and her friend/s. I observed Hayley many times at different competitions and she had many interactions with the other competitors and seemed to know many of the people there. Hayley enjoys the competitive aspect of her sports and particularly enjoys receiving recognition or rewards for her efforts:

> Interviewer: What do you like about [your sport]?
>
> Hayley*: Mostly getting the ribbons and the medals.*

In summary, Hayley has many bonding relationships as part of her social network and these include a mix of individuals who play informal and formal support roles in her life. While Hayley's connection to her disability community is similar to Phoebe's, where disability organisations provided an avenue for her to see her friends, Hayley also saw her friends outside of the disability setting; often visiting each other houses. Hayley's formal supports significantly facilitated her engagement in physical activity through practical support. Through the provision of support, Hayley has also developed friendships with her formal supporters and whilst hard to judge, these friendships appeared to be reciprocated. Hayley's informal supports, family and friends, provide practical and emotional support regarding her physical activity.

Daisy: experiences of health focused norms

Daisy is a shy young woman who lives with her family in an urban area and works one day a week. Daisy's mother supported her during the interviews and she often drew on her mother to respond on her behalf. Given Daisy's tentative communication style and the limited time we spent together it was difficult to explore her experiences of physical activity and social support fully.

Daisy, similar to Hayley, is devoted to her dog and walks her at least once a day on her own. They sometimes stop at a local park to play ball. Her dog is a large part of her life and her "*best friend*". Daisy also takes her dog to training every week. Daisy's mother feels that Daisy has become more confident since starting this training. From our discussions, I understood walking her dog gave Daisy a sense of independence. Talking about her pet also appeared to facilitate a greater sense of comfort and confidence in my interactions with Daisy.

Daisy and her mother prioritise developing Daisy's independence. As part of this, Daisy has a support worker one day a week who help her with activities of daily living (e.g., grocery shopping, taking the bus, cooking) and to attend the gym or swimming. Daisy enjoys attending the gym and using the different equipment:

> *I like the bike, rowing machine and the cross fit one.*

Daisy also engages in a range of other organised physical activities including disability and non-disability organised activities. Daisy's participation in these activities was supported by her mother who organised the practical components including transport. It was unclear if she experienced other types of social support during these physical activities.

Consistent with some of the other participants, Daisy attended a formally organised social group run by a disability organisation that organised events (e.g., dinner, movies, shows) and aimed to promote the development and maintenance of informal connections. Although Daisy did not discuss these activities in detail, she gave the impression she liked going there.

Within Daisy's family network, being active and healthy is a valued practice and the norm; Daisy's family members participate in sport and regularly attend the gym. In particular, Daisy's mother emphasised her view about making health a priority and gave reference to extended family members she saw as unhealthy. In keeping with this, Daisy's mother organises for her to participate in a range of physical activities. From our discussions, I gained a sense that the network connections beyond Daisy's immediate family were limited; Daisy did not describe the people she knew at key events as friends but rather as "*the people at* [place]".

It was difficult to gain a comprehensive understanding of Daisy's social network due to the limited time we had together. Daisy's network consisted mostly of her family with some connections to the disability community as well as her local community (e.g., dog training, employment one day a week and training for sport). Beyond family members, Daisy described her relationships with the other people she knew as acquaintances rather than friends. Exploring her informal support, the social norms within Daisy's family network emphasised healthy behaviours and this was reflected by the physical activities her mother sought out for her to participate in. Daisy's family was a key source of informal support that provided practical support regarding transport and emotional support.

Matthew: physical activity and social support intrinsically linked

Matthew is in his early 30s and lives in an urban coastal area. He spends his time between his mother and father's house; they live a short drive away from one another. Matthew also has a sister who he visits regularly. Matthew works one day a week as a labourer and as part of this role he receives support from a paid support worker who provides transport and assists him in his work. Matthew is a sports fan and enjoys watching sports on television. He has a "*good mate*" – Jack, who he visits regularly to watch football and play table tennis with.

Matthew's social network includes his family and friends, many of whom were part of the broader disability community connected through a network of formal disability service organisations. Matthew has attended these organisations for many years and does not recall why he started attending or if he was active in the decisions relating to his engagement.

Three days a week Matthew attends a day service focused on providing recreational and physical activity opportunities including self-defence, golf, drama and the gym. The organisation provided practical support, in the form of transport to activities, and a social setting in which he could spend time with his "*mates*":

> *Matthew talked about [his sport] and how he enjoyed having his friend to play with; he liked it when his friend was joking around with him while they were playing and calling him by his nickname. Matthew rarely sees this friend outside of the organisation.* [Research journal]

Matthew also attends an organisation that organised regular Friday night activities for people with disability (e.g., going to the movies, going out for dinner, going to a concert), with the aim of supporting individuals to develop and maintain friendships. He also participates in bowling once a week which organised by another formal organisation; he has been attending and playing on the same team for many years. In a photograph he provided, Matthew is standing at the ball return, holding his bowling ball, with the brightly lit bowling lanes in the background. He is smiling and wearing the team uniform. Bowling sometimes has competitions which he attends and enjoys. He proudly told me of his win and high score when I asked how the competition had gone:

> Interviewer: What else happened at bowling?
>
> Matthew*: I just go for, I got three strikes in a row and because I got four turkey*
>
> I: A turkey?
>
> M: *Yea … It's for the scores, for bowling. Yea. Its three strikes in a row.*

Matthew expressed interest in starting a sporting team with his friend but was not sure about how to progress with their plans; requiring equipment, somewhere they could play, and someone to help them organise for everyone to come (they were not interested in organising this). It seemed these plans were talked about between Matthew and his friend but they had not yet sought help to organise it.

Similar to Daisy's family experience, Matthew's family also value physical activity and being healthy in such a way that it has positively influenced their behaviour. For example, Matthew and his mother regularly go for walks and swimming. His mother provides practical support (e.g., promoting to get ready, driving him to the pool) as well as the emotional support needed to encourage Matthew to attend. Matthew likes to go swimming, but given the choice, he would prefer to stay at home.

Overall, Matthew enjoyed being active and had an extensive social network that consisted of informal and formal supports drawn from his involvement in a number of organisations. For Matthew, social support and physical activity were closely linked – time with family and friends was often connected to engagement in physical pursuits. Similar to Phoebe, Matthew also mainly saw his friends through a disability setting with only one friend with whom he spent time with outside a disability setting. However, Matthew was also able to draw on bonding and bridging relationships through his workplace and connections with neighbours that extended beyond his disability network. Matthew's understanding of friendship was grounded in having shared interests and doing things together.

Greg: family support important

Greg is a young man in his early 20s who lives with his family in a large rural area. Greg has a companion, who his mother describes as his best friend, called Marg, who also lives with disability. Greg and Marg have been friends since school and regularly attended some of the same activities together. Greg and his family also have a dog and Greg is involved in looking after her and walking her with his family members.

Greg uses gestures, some words and an iPod to communicate; I could understand most of what he communicated. During our discussions, Greg would say a word or two, or point to something on the iPod (e.g., a photograph) that prompted his mother to talk about that topic. This method of communication appeared to allow Greg to direct the conversation and discuss the things important to him.

The majority of our discussions occurred in the context of talking about the images and videos Greg had taken. These included existing photographs and those taken for the research. Greg was able to pick out photos about a topic or indicate his favourite photo and then prompt his mother to discuss it. For example, I asked Greg about his sport and he identified a photograph of him with his coach and Marg, in which Greg is standing in the centre with his new coach who is giving a thumbs up. He and Marg are standing with their arms around Greg, who along with his coach, is wearing a brightly coloured t-shirt in Greg's favourite colour. This prompted his mother to tell me about Greg's new coach.

Greg received formal support from a number of sources. During the week, Greg was involved with a disability organisation that provided a day service and offered access to physical activity options including, swimming and walking. Greg's was also involved in tennis and personal trainer sessions at the gym; both physical activities involved support from an individual in a paid role with an organisation. Greg was also involved in other disability organisations including a drama club, which he attended with Marg.

Greg received a large amount of his social support from his informal social networks. Greg's family offered emotional support (e.g., attending and providing encouragement at Greg's sporting competitions) and practical support (e.g., organisation and transportation to a physical activity) for Greg to be able to participate in physical activity. Similar to Daisy and Matthew, Greg's family was focused on their health and as a result family activities were often oriented around physical activity. Greg also had regular sessions with a personal trainer at the gym who provided formal support outside of the disability community. However, the personal trainer stopped working at the gym and Greg's family were making arrangements to continue his workouts at home with the support of his brother, who was going to develop a training plan for him.

Greg had connections with his local community, reaching beyond the disability community, and included attending the local youth group and volunteering with a local service. Greg proudly shared photographs of when he was asked to join in parade practice, where Greg is at the end of a line with six other people in uniform. Although Greg is not wearing a uniform, he has a name badge on his shirt. They are all standing with their arms by their side looking forward.

To summarise, Greg's social network consists of his immediate family and close friends, formal supports as well as bridging connections with his local community. Greg has contact with close friends outside of a disability setting, often having people over to his house and visiting friends at their house. Similar to other participants, Greg engaged with formal supports for his physical activity; the support provided through this avenue related to practical support as well companionship. The support Greg received from his informal supports to participate in physical activity included emotional, practical and companionship support. Greg also reciprocated support, often providing emotional support to a friend to be active. Similar to Daisy, Greg also experienced health focused social norms within his family network which resulted in family activities often involving physical activity.

6.2 Conclusion

The vignettes presented in this chapter represent a snapshot of each of the participant's lived experiences of physical activity and social support. In doing so, they addressed the aim of this chapter, to explore participants lived experiences, particularly their experiences of social support.

Participants described their engagement in a diverse range of physical activities and experiences of different forms of social support. In considering the relationship between social support and physical activity, this chapter has presented examples that clearly demonstrate experiences of social support facilitating physical activity as well as social support that stemmed from participation in physical activity. Chapter 7 will now examine these relationships in more detail, through an analysis of themes that emerged.

Chapter 7 Experiences of using social support to engage in health practices

In Chapter 6, a brief narrative examination of participants' lives was presented that explored their experiences of social support and physical activity. This 'set the scene' for further investigation of the relationship between social support and physical activity. This relationship will be explored in this chapter, which presents a thematic analysis of the data described in Chapter 6 through vignettes. The thematic analysis asked *What was the relationship between social support and physical activity as experienced by participants?*

Key themes are represented in Figure 7.1, which draws on Lunsky's (2006) social support model to provide a framework to group the themes. As discussed in Chapter 2 (see Section 2.3), the model proposes social support can be influenced at three levels (individual, relationship and community). Under the individual level, themes represent experiences of participants at an individual level that impacted their social support and their use of social support to engage in physical activity. At the relationships level, themes reflect influences of social support in relation to the interactions between individuals, the nature of these interactions and the type of support that is received, perceived or withheld. Under the community level, themes explore the setting in which social support occurs and the social norms which influence experiences. Where appropriate, relevant literature is draw upon to inform the discussion of the themes.

Consistent with the previous chapter, participant quotations are reflective of their language and method of communication. The focus of the discussion is on participant experiences as described by them. However, at times, it was necessary to consider the

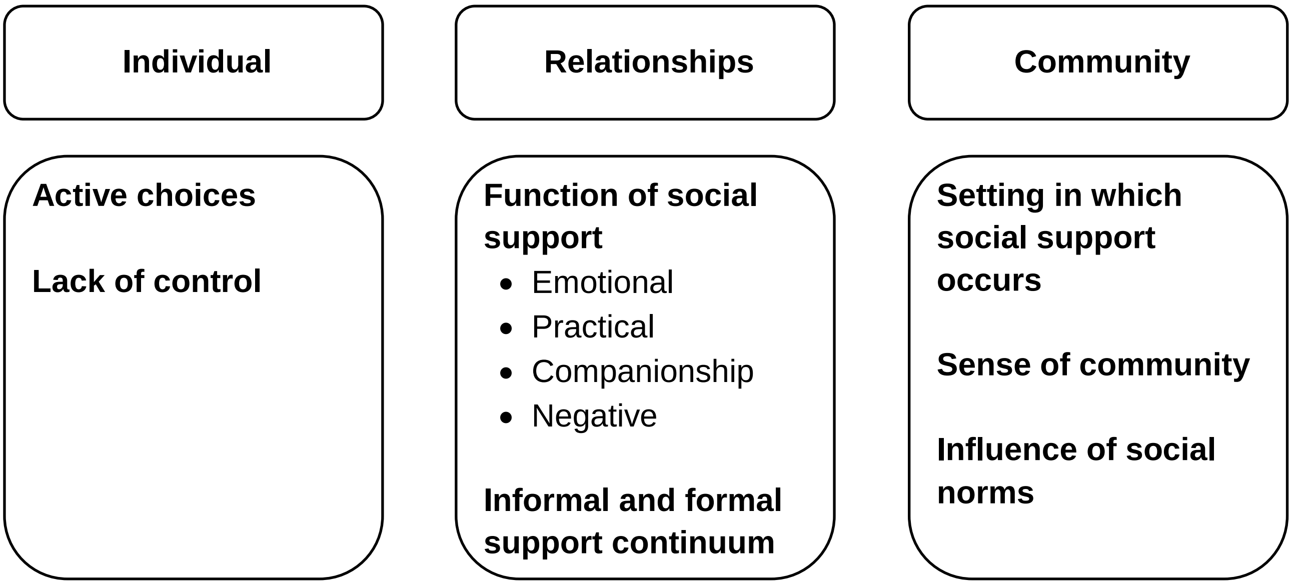

Figure 7.1 Summary of themes.

perceptions of others to fully understand a participant’s perspective; the views of people who offered support to participants during data collection are presented as research journal entries. To maintain participant’s confidentiality, photographs have been replaced with descriptive text.

7.1 Individual level of social support

At the individual level, two key themes emerged from the data: the individual’s ability to make active choices to draw on social support to engage in physical activity; and their perceived or experienced lack of control in their lives related to engaging with social supports and physical activity.

Making active choices to use social support in physical activity

A key theme arising from the data was the different choices made by participants regarding their use of social support to engage in physical activity. In some instances, participants made active decisions to seek and gather support to facilitate their participation in physical activity. For example, as discussed in his vignette, Mark rang his friends and actively planned to walk with his friends. Conversely, Barry rejected offers of support to facilitate his physical activity, preferring to be active independent of others and to seek social support elsewhere. Other participants also experienced times when they preferred to not engage in social support. When at the gym, Matthew preferred to focus on his workout rather than socialise with the group of people he went with:

> Interviewer: Do you chat with the people around you [at the gym]?
>
> Matthew*: No sorry*
>
> I: You just do the workout?
>
> M: *Yep*

Matthew focused his efforts on physical activity in other activities. His mother and sister invited him to walk with them or join them for a swim, which he enjoyed as it gave him the opportunity to “*work up a sweat*”. Their support to Matthew was more practical: Matthew’s mother preferred he did not walk or swim on his own for safety reasons. Matthew did not seek emotional or companionship support during walks, preferring to run ahead of his mother and sister, waiting for them at agreed upon stops.

Although most participants experienced social support to engage in physical activity, participants also experienced times when physical activity had become a way in which social support could be gathered. Participants made choices to attend these physical activities so that they could engage in social connections. For some, physical activity was the only avenue through which they saw their friends, and physical activity played a very minor role in their motivation for attending that activity. This was particularly true for Phoebe:

> *Phoebe sees her friends primarily though her organised activities, although she does see some of her friends at multiple activities over the week, she expressed a desire to be able to catch up with friends outside of these.* [Research journal]

Lack of control

In contrast to participants' choices and their own influence on social support is the lack of control participants experienced. Some participants experienced lack of control as a result of decisions being made about them or decisions being made that directly related to them. A lack of control over some aspects of life can result in lost connections, which can have far-reaching consequences when one does not feel in control of other aspects of their life. Such a lack of control can be perceived as a negative experience of change, particularly of change that is unexpected. For example, unscheduled turnaround of paid support staff or the loss of friends who usually attend an organised activity can cause stress and anxiety and may result in diminished contact with these individuals in the future. A member of Matthew's bowling team left and he subsequently lost contact with a decade-long teammate:

> Interviewer: Do you play in the same team every week?
>
> Matthew: *Every Saturday and because we don't have Kirsty*
>
> I: *Did she leave?*
>
> M: *Yep*
>
> I: *Do you get to see her anymore?*
>
> M*: Nope*
>
> I: *Do you miss having Kirsty on your team?*
>
> M: *Yea*

Related to lack of control are the negative emotions that occur when participation in activities finishes or when contact with a favoured person is no longer possible. This is particularly relevant when changes to formal support are made:

> *Hayley often wonders about past support staff and wishes she could get back in contact with them. She had developed*

> *friendships with these people; they had spent considerable time together and were a source of companionship support to Hayley. However, their relationship ceased when they stopped working at the organisation and a new paid support staff member took on this role. Although the support worker may be replaced, the connection and relationship they had is lost. Hayley had to start afresh with a new staff member, building rapport and a relationship with them.* [Research journal]

Phoebe had recently experienced loss of connections as a consequence of changes to her attendance at a class, which she associated with upsetting memories. Phoebe had been attending this class for many years but began to struggle with the constant turnaround of other students (who were leaving when they finished school/university) and the loss of connection that occurred, as this was the only avenue through which she saw these individuals:

> *Phoebe is really missing her old class at the moment and she says this is mostly because she misses seeing her friends and teachers.* [Research journal]

She replaced this class with another where she was able to have more contact with her established contacts; however, she still wanted contact with the people from her old class, including her teachers. Phoebe gave the impression she did not cope with these changes well.

7.2 Relationship level of support

In relation to support provided through relationships, two key themes emerged during the data analysis. First, participants accessed and experienced a range of social supports and social connections that provided access to the key functions of support, particularly companionship, emotional support and practical support. Second, among participants' existed the unclear distinction between informal and formal supports; often the roles between these supports overlapped and were not mutually exclusive.

Functions of social support

Participants enjoyed spending time with their family members and friends through shared activities (e.g., walking, participating in organised activity together or going for coffee) during which they accessed emotional support and companionship. In addition, participants experienced practical support, often related to transport and the organisation of activities. Some of this practical support was related to participants' experiences of disability and was essential to facilitate access and participation. It should be acknowledged that participants often did not elaborate on other areas of their life where they used support related to their experience of disability (e.g., cooking, shopping) although these were explored if they came up in conversation.

Some participants experienced negative supports from their social relationships and for some this was particularly prominent in their lives. Risk adverse behaviour of support people can prevent or restrict participants' opportunities to be active and maintain connections made through physical activity (Simplican et al., 2015). For participants, this resulted in reduced opportunities to be active or to engage with their friends. For example, as described in Chapter 6, Phoebe was particularly conscious of the influence of her parents on her ability to engage in physical activity and social opportunities. She talked often about her perceptions of the negative influence of over protective behaviour on her participation in activities. The concept of negative support has not received a great deal of attention in intellectual disability research investigating social support (Lunsky & Benson, 2001) but has been identified within the context of physical activity (Alesi & Pepi, 2017; Frey et al., 2005; Taliaferro & Hammond, 2016).

Participants experienced many connections across the different experiences and activities in which they engaged—a finding consistent with the literature that suggests people with intellectual disability have wider social networks than previously found through proxy-based research (Forrester-Jones et al., 2006; Robertson et al., 2001; van Asselt-Goverts et al., 2013).

A continuum of informal and formal support

It was difficult, at times, to identify if the relationships participants were describing involved individuals in an informal or formal capacity, partly because participants themselves often did not distinguish between informal and formal support. Participants often described formal relationships, considered in the literature as paid support from an organisation (Lipman & Longino, 1982), that had components generally associated with informal support (e.g., providing companionship). This was exemplified by Mark, who considered everyone he met as his friend, including people in formal positions (as detailed in Chapter 6). Equally, participants also discussed informal relationships that had components often associated with formal support. For example, as outlined in her vignette, Daisy's mother facilitated Daisy's support and contact with organisations and took on, what could be considered, a formal role of service facilitation.

Therefore, it is proposed that through the data there emerged a continuum of support, with informal support positioned at one end of the continuum and formal support at the other. Moving along the continuum informal support begins to encompass roles traditionally associated with formal support and formal support takes on roles associated with informal supports. A finding positioned on the informal end of the continuum related to the value placed on being active as a family by informal supports. As highlighted in the vignettes, being active as a family provided a number of functions of support including practical support, emotional support and encouragement to be active. Often families used physical activity as a way to spend time together and embedded healthy behaviours into their lives. Greg described his family holidays at the beach as very physical activity focused where they walked along the beach together and engaged in other physical activities. A favourite photo of Greg's was taken from one of these holidays and served as a reminder of the fun time he had while being active with his family.

Moving along the continuum, where roles between informal and formal supports start to blur, the following finding reflects the shift towards formal supports providing support often associated with informal support. Formal supporters (often paid support staff at disability organisations) who are traditionally viewed as providers of only practical support, also provided informal support through friendship, resulting in an exchange of emotional and companionship support. For example, a formal supporter facilitated emotional support for Mark to start walking, by contacting his friends and asking them to provide encouragement through photos and videos.

Additionally, companionship support was provided by formal supports. Companionship can arise from the provision of practical support; often paid support staff attended an activity to provide practical support and participated in the physical activity. This often added to the enjoyment of the physical activity for participants. As outlined in his vignette, Matthew enjoyed the companionship support he experienced when paid support staff at his disability organisation joined in on games of golf.

At the far end of the continuum, formal supporters also impacted on the social support-physical activity relationship for participants, often in a way that restricted physical activity. This theme was predominantly highlighted by family members of participants, drawing attention to the financial cost of activities, transport issues, and cost of disability support as examples of these barriers that negatively impacted on participants' ability to engage on that activity. Participants also experienced the negative impact of a risk adverse attitude from formal supports. This was particularly evident through the provision of services whereby bureaucratic processes added stress and other burdens to individuals and their families resulting in reduced access to activities:

> *Phoebe's mother spoke about why Phoebe had stopped attending an organisation. She said the organisation fostered dependence and everyone needed to fill out a new medical form from their doctor or specialist for insurance purposes. Phoebe's mother (Phoebe indicated she agreed with her mother) felt the form was too intrusive, it asked very personal questions that were not relevant to the type of activity Phoebe was going to be doing.* [Research journal]

7.3 Community level of support

In relation to support drawn from communities, themes emerged about the setting in which support occurred and the influence of social norms on experiences of support in these different settings.

The setting in which social support occurs

Participants experienced social support in a range of social settings; however, experiences were primarily based in segregated disability settings or within a public setting. Commonly, participants saw their friends at an organised activity (e.g., seeing a friend at day service organisation); this implies their friends also lived with intellectual disability. This finding is consistent with literature which reports people with intellectual disability tend to spend time with their friends within a public domain as opposed to a private setting (Emerson & McVilly, 2004) and are more likely to be friends with other people with disability (Knox & Hickson, 2001; Verdonschot et al., 2009). As described in Chapter 6, some participants did talk about having friends visit or visiting their friends at home; this was often facilitated by practical support from support people in the participants (or friend's) life. Simplican et al. (2015) suggest the trend towards social contact taking place in a segregated setting may be due to family members (or individuals) need to maintain a sense of familiarity and safety within their disability community. Engaging with the wider community may be seen as unfriendly, it may also incur additional costs or support requirements.

Despite a tendency for participants to engage with friends in segregated settings, most participants did engage outside their local disability community. It was seen in the vignettes that some participants worked in mainstream employment (some with support) or regularly engaged with their local community through community organisations and events that were not disability specific. Some participants had support people who actively sought to engage them in activities beyond their disability community. Social networks research highlights the importance of having bridging relationships (i.e., connections outside of an individual's normal social network) (Szreter & Woolcock, 2004). These relationships offer an opportunity for individuals to experience different social groups and settings and therefore a broader range of experiences and information which can influence health (Granovetter, 1983; Kavanaugh et al., 2005).

Sense of community

The sense of community provided in disability settings extended beyond the provision of a network of people who attended the same organisations, and instead reflected a broader sense of connections across activities among individuals sharing mutual friends. These relationships consisted largely of bridging relationships from which participants could draw support. Feeling a part of this community meant participants were not anxious or stressed about having to meet new people at new activities or events, which may have occurred without the support and companionship provided by members of their community. They had existing social connections and supports they could draw on for support, even during participation in new activities:

> *Phoebe started at a new exercise class, the one she had been attending was quite far from her house and she did not know any of the other exercise students, she found the class "isolating". Phoebe was excited to be starting at this new exercise class as she knows many of the other students through her other connections in the disability community.*
> [Research journal]

The disability community may have a positive and negative impact on individuals and the support they could draw on. In taking advantage of the disability community networks, informal and formal supports, when seeking activities for individual's, may seek activities that are viewed as 'safer' options because the individual participates with likeminded people aware of disability specific considerations. A lack of effort or support may prevent engagement beyond the intellectual disability community.

Influences of social norms of social networks and communities

Social norms played an important part in participants' social support and therefore physical activity. As previously discussed, informal supports were a source of positive support for participants and prompted participants to be active. Thus, the social norms embedded within social networks and communities can have a positive influence on participation in physical activity. For example, family members' attitudes and behaviour towards health and being healthy are very influential. Family members may have healthy lifestyles and take steps to support individuals to be healthy. This often leads to informal supports fostering an environment where shared family activities are healthy, an environment where health and physical activity is prioritised and family members lead by example. This was seen through many of the participants' vignettes presented in Chapter 6. For example, Daisy's mother was conscious of creating an environment that was conducive to health:

> *Daisy's mother shared her views on healthy lifestyles; she strongly prioritises health in her household. She made active decisions to seek out healthy options and had been purposeful in the activities she supported Daisy to participate in with many having a health promoting component. Demonstrating the family commitment to a healthy lifestyle, at the start of an interview, Daisy had just been on a walk with her dog, each of Daisy's siblings had just returned from sports training and her mother from the gym.* [Research journal]

Social norms may also negatively influence behaviour. Individuals may perceive that they are unable to do an activity or task because of their disability, particularly if the activity is viewed by others to be 'unsafe'. This may be particularly difficult for individuals to experience because it can be viewed that safety is intrinsic to their impairment, and invariably affects their ability to participate in some activities. Regarding safety, it can be difficult to assess whether concerns were valid or if support people are being overcautious. In some instances, it may even be unclear whether individuals are able to assess their own abilities or how deeply they are impacted by social norms about their capabilities. For example, Matthew felt he was 'able' to go on a walk but he was discouraged to do so by his parents:

> *Matthew's parents live close to each other, only a three minute drive and 15 minute walk. Matthew tells me he occasionally walks between the houses on his day off (he is on his own for the majority of the day while his parents are at work). He tells me about these walks in hushed tones and with a cheeky grin as he knows his parents do not want him to be walking on his own.* [Research journal]

7.4 Discussion

The themes presented in this chapter highlight the myriad ways social support was used to facilitate participation in physical activity by participants. The themes also demonstrated that the relationship between social support and physical activity was multidirectional, in that social support can facilitate physical activity and physical activity can enable social support.

These findings can be used to further refine the key elements of social support for people with intellectual disability. First, is the notion that the role of social support is *dependent on the individual and their circumstances*. Participants had their own individual preferences and approaches to social support and physical activity and, at times, made decisions to ensure the social support they experienced met their needs. However, support, at times, went beyond the preferences of the individual and reflected their *needs*. There is a ‘fine line’ that must be negotiated to reflect both the preferences and needs of people with intellectual disability in terms of practical support, emotional support and companionship. The constant negotiation between individuals, informal support and formal support requires skills and patience to ensure a balance is met and may add further complexity to these relationships.

The concept of *informal and formal support occurring along a continuum* and reflecting a complex and multifaceted relationship was proposed in this chapter. Both informal and formal supports provided practical support and companionship support that also encompassed emotional support and a distinction between the support experienced from informal and formal support was not clear. The continuum also represents the blurring of roles in these relationships; formal supporters can provide support traditionally associated with informal support and informal supports can provide support often associated with formal support. In the findings of this chapter, this was often reflective of formal supporters providing practical support that led to the provision of other support; they assisted with transport to an activity as well as emotional and companionship support, joining the participant in the activity and encouraging their participation.

Reinforced in this chapter was the *social stability* of social networks. The stability of participants’ social networks was influenced by change that impacted on the support they could draw from their networks. Participants tended to have fluidity in their relationships, particularly concerning formal supports. Formal support often changed frequently and more often than not, resulted in the relationship ending. While change is a common occurrence in life, for people who have little control over their life, unwanted change can be a challenging experience and Thoits (2011) proposes it can negatively impact health.

Adding to the key elements of social support for people with intellectual disability, the findings of this chapter highlighted the *influence of social norms* on social support experiences. The social networks of participants informed the social norms they experienced. The social norms experienced by participants had both positive and negative impacts on social support and physical activity; however, despite this influence this is an area that has not been researched for people with intellectual disability. In this chapter, a positive experience of social norms on social support and physical activity involved informal supports modelling a healthy lifestyle; however, this is a norm that can be demonstrated by formal supports as well. Despite the potential this may have for the health experiences of people with intellectual disability, researchers have found formal support organisations often are not supportive of their staff in such endeavours (O'Leary, Taggart, & Cousins, 2016).

7.5 Conclusion

This chapter aimed to inform understanding about how people with intellectual disability use social support to engage in a health practices, physical activity. Key findings related to the influence of social roles and social norms, feelings of belonging and feelings of control on physical activity participation. The next and final chapter brings together the findings of the thesis and discusses implications for practice and future research directions.

Chapter 8 Discussion

This thesis aimed to answer the research question: *What role does social support play in the health practices of people with intellectual disability, specifically in relation to their participation in physical activity?* To address this question, the thesis presented a review of the social support and physical activity literatures, identified knowledge gaps, and offered an alternative approach to understanding health behaviours, such as physical activity, using health practices. The research presented sought to identify good practice qualitative research and to embrace an inclusive research approach. Chapter 4 presented a ‘blueprint’ of inclusive research practices for qualitative research which was used to guide the thesis’s methods. Incorporating these inclusive research practices enabled the collection of qualitative data that generated meaningful and in-depth findings related to the seven participants, which were presented using vignettes and key themes in Chapters 6 and 7, respectively.

Findings suggest participants experience myriad social supports in complex and diverse ways. This chapter synthesises and critiques the findings presented throughout this thesis in the context of the research’s three key aims. First, the chapter reflects on the understanding of social support developed in Chapters 6 and 7 and examines the role of social support in relation to physical activity participation for people with intellectual disability. It then considers the utility of the inclusive research approach taken, in relation to the impact this approach had on the thesis methodology, and inevitably, findings. Finally, through its attempts to develop an understanding of social support for people with intellectual disability, this thesis has generated many questions deserving of further enquiry. These questions are explored throughout this chapter and the implications for practice and directions for future research will be discussed in the context of the strengths and limitations of the study design used throughout the doctoral research.

8.1 An enhanced understanding of social support

A key aim of this thesis was to develop a deeper understanding of social support for people with intellectual disability. To address this aim, a summary of the key elements of social support for people with intellectual disability was developed, initially derived from the literature. This initial summary was refined during development of the vignettes and thematic analysis. The following section will synthesise and appraise these key findings in the context of the overarching thesis.

A key element of social support for people with intellectual disability is the complex nature of informal and formal support, and the notion that such support occurs along a continuum (where informal support is at one end and formal support the other; moving along the continuum, informal support begins to encompass roles traditionally associated with formal support and formal support takes on roles associated with informal supports). There is a 'blurring' of the type of support provided by informal and formal supporters due to the complexity and diversity of the roles they play in the lives of people with intellectual disability. At times, formal supporters provide informal support, and informal supporters take on the roles traditionally associated with formal support. Within the literature, this continuum has not been explored fully. Bigby (1997) and Meltzer (2017) explored the notion of informal supports providing support traditionally understood to be provided by formal supports but the other end of the continuum, where formal support crosses into informal support, has not been investigated.

Encompassed within the complexity of support roles are the differing understandings of friendships held by people with intellectual disability and their supporters (as well as by researchers) and how these different understandings can affect experiences of social support. Previous research has highlighted that there is such a difference but has not consider the impact of this on social support (e.g., Clegg & Standen, 1991; Jahoda & Markova, 2004; Lippold & Burns, 2009). Such 'clashes' of understanding can result in tensions within the social support dynamic, particularly when an individual considers a relationship to be friendship, but the other party considers it to be within the boundaries of a formal relationship involving a 'client'. This complexity, and the inevitable impact it may have, is yet to be investigated in the literature; however, it is critical to progressing understanding of the role social support plays in health practices such as physical activity. This thesis has contributed understanding of the need to consider these elements (friendship, unequal relationships) in research and in practice. Future research must investigate the nuances of these relationships, and those working with people with intellectual disability should recognise the complexities individuals experience when navigating the relationships from which they draw support.

The fluidity of relationships and social networks is another critical element to understanding social support for people with intellectual disability. This fluidity may be experienced in terms of shifting contact (that can result in lost opportunities to see each other) with friends and formal supports. With regards to the latter, when formal supports inevitably change professional positions, there can be a lack of impetus to continue a relationship that has been viewed as one based in work, rather than one resulting in friendship. Further, formal supporters are unlikely to experience social instability to the same extent as people with intellectual disability, and therefore may place less value on the relationship and be less willing to make efforts to maintain the relationship. In one of the only studies to report on social stability for people with intellectual disability, Newton, Olson, and Horner (1995) interviewed paid support staff who had continued a friendship with an individual they had supported in the past. The staff reported facing many logistical barriers in maintaining the friendship (e.g., they had to initiate contact, organise an activity to do together, organise transport); however, the main driving factor was the staff member believed the relationship to be reciprocated. For those who lose a connection, the resultant loss may contribute to people with intellectual disability feeling a lack of control, and subsequently, coming to view and experience support differently in the face of inconsistent relationships arising from staff turnover.

Challenges related to lack of control and lost connection have been undervalued in research involving people with intellectual disability (Björnsdóttir, Stefánsdóttir, & Stefánsdóttir, 2015). Consequently, we know little about the long-term impacts of social instability on the internal and external experiences of individuals. Thesis findings suggest that the impact could be substantial, although the study design limits capacity to draw firm conclusions. However, it can be confidently stated that more work must be done by researchers to understand this phenomenon, and to inform initiatives aiming to improve or increase social support for people with intellectual disability. Given the sensitive nature of discussing friendship and lost connections with individuals, an inclusive research approach that appropriately responds to the ethical considerations of exploring such content with participants is essential to future, ideally qualitative, research that contributes better understanding of these issues.

Another important finding relates to social networks and the connections an individual may have with a disability community. The literature often overlooks this active and broad network of support, particularly for those who engage regularly with disability support organisations. The disability community described by participants was holistic and although the connections being made were fostered in an organisational setting, this community should be considered more than merely organisationally based. Instead, it is reflective of a personal community network, that is a “set of active community ties, is usually socially diverse, spatially dispersed, and sparsely knit” (Wellman & Wortley, 1990, p. 559). The notion of a personal community network focuses on the features of community connections and how support flows through them. For participants, these communities offered a network from which they could draw support. They also give weight to the larger social networks people with intellectual disability report (Forrester-Jones et al., 2006; van Asselt-Goverts et al., 2013) compared to data provided by proxy respondents (Robertson et al., 2001; Verdonschot et al., 2009), who may not have considered the disability community as important. Personal community networks have not yet been investigated in the intellectual disability literature but may be critical to understanding the social networks of people with intellectual disability, as well as the support they draw through these networks. The notion of personal communities requires further investigation by researchers as they may be pivotal to developing a clearer understanding the breadth of the support for people with intellectual disability. When working with people with intellectual disability it is important to acknowledge that these connections have the potential to enhance interventions aiming to improve health practices for people with intellectual disability.

8.2 Understanding the role of social support in physical activity participation

Three key findings arose that help us to better understand how social support is related to physical activity. First, is the utility of the mechanisms proposed by Thoits (2011) to understand the relationship between social support and participation in physical activity. Second, the nuances of companionship support must be described and understood in order to understand this function of support on health practices. Third, there is a need for an alternative approach to designing health promotion initiatives based on the principles of inclusive research. This section will briefly touch on each of these three points and reflect on the utility of taking a health practices perspective.

Mechanisms of social support proposed by Thoits (2011)

Thoits (2011) provided a framework to understand how social support influenced physical activity for participants. In particular, the key mechanisms she uses to connect social support to health were essential to understanding the role of social support on physical activity participation; namely, social roles, social norms, experiences of belonging and companionship and control. In the literature review presented in Chapter 2, a key question was proposed in response to these mechanisms: *Do the proposed mechanisms contribute to enhanced understanding of experiences of physical activity among this group?* The following discussion will attempt to address this question.

A key mechanism reflective of the themes presented in Chapter 7 was *behaviour guidance, purpose and meaning*, which reflects that the role an individual identifies with in a relationship informs their behaviour and individual's relate their significance to other people (Thoits, 2011). In Chapter 7, it was highlighted that participants identified with certain roles in relationships that negatively impacted their physical activity participation. Specifically, the concerns of informal and formal supports related to safety may have located participants in dependent roles that compromised their perceptions of their own ability to engage in social support and physical activity opportunities. This experience has been previously reported for people with intellectual disability in the form of negative support (Brooker, Mutch, et al., 2015; Taliaferro & Hammond, 2016). This mechanism also helps to explain the experiences of individuals who hesitated to organise their own activities; participants may have felt that organisation extended beyond their perceived role and that they even lacked the skills to perform the necessary tasks to organise people and events. This perceived lack of capability is further explained by *self-esteem*, in which an individual's beliefs about their competence and worth may impact their health practices. Supporting this, Alesi and Pepi (2017) and Temple (2007) found people with intellectual disability seek guidance and want to be shown how to be active and have reported not having this guidance restricts their ability to be active.

The *social comparison* mechanism provides another useful narrative through which the experiences of participants may be understood. This mechanism proposes social norms are informed by an individual's social network; informal and formal supports as well as their broader community enforced many of the social norms experienced by participants. As already discussed, participants reiterated, and at times even embraced, norms relating to safety and their abilities as an individual with disability. The disability community, while potentially contributing to these norms, was also often a supportive environment for participants. Their local disability community was inclusive of participants needs, however, it is also important for people to also be included and engaged with their wider community (Bigby, 2012). Inclusion with the wider community has been associated with improved outcomes relating to health and wellbeing as well as being a right advocated for under human rights conventions (Simplican et al., 2015). However, individuals' engagement with their wider community and the subsequent reshaping of their social norms should be considerate of their preference and needs. For example, when Phoebe branched outside of her local disability community, she felt isolated; she may have benefited from additional supports to support her through this experience.

Belonging and companionship helps to explain the positive impact a sense of belonging and companionship can have on social support and physical activity. Participants received this support from family, friends and paid support staff as well as their local disability community that fostered a sense of belonging and inclusion that positively influenced both social support and physical activity. Although not directly investigated in social support and physical activity research, this notion reflects one of the most commonly reported facilitators of physical activity for people with intellectual disability – the opportunity for social connections (Dixon-Ibarra et al., 2016; Temple & Walkley, 2007).

A *sense of control* reflects an individual's ability to cope with challenges and change; a lack of control can result in a negative effect on health (Thoits, 2011). Participants often felt they had no control or had a negative experience of control particularly when it came to dealing with change. This can be a particularly challenging experience for an individual who has or feels they have little control over most aspects of their lives. As a result, change hindered participants' experience of social support and therefore the social support available to support physical activity engagement.

In sum, the use of these mechanisms and their applicability to people with intellectual disability is deserving of attention from future researchers; it may be an important avenue to explore to continue to build an understanding of this relationship.

Nuances of companionship support

Companionship support is a key function of social support that appeared to facilitate physical activity. Although previous research (e.g., Dixon-Ibarra et al., 2016; Temple & Walkley, 2007) has identified the importance of having someone to be active with, the conceptualisation of 'companionship support' has not been fully explored. As a result, little attention has been given to unpacking the role of companionship in the lives of people with intellectual disability including the potential positive and negative impact on health practices. There existed a 'fine line' between the practical support participants *preferred* (i.e., emotional support, companionship) and the reality of the support they *needed* to facilitate their physical activity (i.e., physical support: transport, organisation). This fine line resulted in tension whereby participants could resent the presence of supporters or feel that others made decisions for them. This tension requires skill and patience to navigate to avoid an individual withdrawing from activities or building resentment towards their supports. There is a need for sensitivity on behalf of the person offering companionship support but given that this might be offered by family members who have multiple roles in the lives of individuals and who are unlikely to have received training to navigate potential conflicts, such sensitivity can be difficult to achieve. Similarly, formal supporters may be focused on their practical support provision at the cost of companionship. In other words, even for the supporters this is a difficult situation to navigate. Ultimately, it is vital that emotional support provided through companionship meets the preferences of the individual while also meeting their practical needs. It goes beyond the data to speculate how this can be best managed by individuals with intellectual disability and their supports; rather, this finding represents an attempt to have an open discussion about the intricacies of companionship and the inherent difficulties that it involves.

Alternative approach to health promotion

To date, health promotion interventions have failed to result in sustained changes in behaviour to improve health (Temple et al., 2017). It is arguable that a corollary to this lack of sustainability is the lack of understanding of the nuanced role that social support can play in changing health practices. The findings of this thesis highlight the complexity of the social support-physical activity relationship and recognise the multidirectionality of the relationship as well as the multitude of roles that informal and formal supporters can and do play in the lives of individuals with intellectual disability. As will be argued in the next section, such an understanding was only possible as a result of the inclusive approach taken by the research. Although potentially pre-emptive of the discussion below, it is worth noting here that to progress health promotion interventions towards sustainability and the achievement of meaningful change, inclusive practices must also be adopted, whereby the views and experiences of people with intellectual disability are prioritised and placed centre to these initiatives. We must extend the notion of researchers needing to adopt a ‘nothing about us, without us’ approach (Charlton, 2000), which is reflective of the social model of disability, to health promotion initiators. By considering the views, experiences and the social context of people with intellectual disability throughout the conception, design and implementation of interventions, these interventions will be more reflective of the needs and experiences of the target population and better equipped to support sustained changes in behaviour.

The health practices approach taken in this doctoral research facilitated a more comprehensive exploration of the relationship between physical activity and social support for people with intellectual disability. It allowed for a more nuanced and holistic approach than has previously been used with this population group when investigating health behaviours. The approach acknowledged the complex individual and social contexts experienced by participants and considered the role structure and choice played in their behaviours. The health practices perspective also aligned with the complexities of individuals lives; acknowledging behaviour does not occur in isolation but a set of practices form the action related to the behaviour. This was particularly relevant given people with intellectual disability often engage with supports to perform actions. Overall, further research using a health practices approach with people with intellectual disability should be considered given the utility of this approach in acknowledging the complexities of the lives of this population group.

8.3 Reflecting on the inclusive research approach and inclusive research practices

This thesis used an advisor capacity approach, and developed, and was guided by, a blueprint of inclusive research practices that focused on including and engaging people with intellectual disability in qualitative research. The advisor capacity approach resulted in improved communication with participants in both written and verbal communication. The blueprint facilitated and supported the active engagement of participants and resulted in a rich dataset that was reflective of participant’s experiences. The following section explores how embracing these inclusive tools addressed the research aim: to identify good practice when conducting inclusive qualitative research with people with intellectual disability.

This thesis has offered much needed clarity regarding ‘inclusive research’ which has variously come to mean involving people with intellectual disability in research as researchers and participants. For the purposes of this research, an *inclusive research approach* was defined as reflecting the focus on *researchers* and inclusive research practices was defined as focusing on the experiences of *participants*. It is important to note that researchers who take an inclusive research approach also often apply the principles of inclusive research to their engagement with participants and in turn use inclusive research practices. Arguably, the distinction made by this thesis is critical to supporting researchers who do not have capacity to take an inclusive research approach but want to embody the principles of inclusive research. Both arms of inclusive research need to be further progressed; however, inclusive research approaches have been more comprehensively developed by the literature (Atkinson & Williams, 1990; Bigby et al., 2014; Walmsley & Johnson, 2003).

The blueprint of inclusive research practices for qualitative research developed in this thesis is offered as one way in which we, as a field, can gain more momentum in this area. The application of these inclusive research practices provides an essential foundation for qualitative research involving people with intellectual disability and reflects the reasonable accommodations researchers need to make to be inclusive of this population group. It is important that as researchers, we create an environment that enables people with intellectual disability to participate in research (Walmsley & Johnson, 2003). Through the use of the blueprint, many of the barriers researchers cite as challenges to including people with intellectual disability in research (e.g., challenges associated with gaining informed consent, differences in communication) can be overcome. This is applicable beyond qualitative methodologies and may be employed by quantitative research methods to overcome similar challenges. The blueprint will allow researchers to be transparent about their methods, consequently opening up dialogue about how to better equip researchers to achieve inclusivity in their engagement with people with intellectual disability. Ultimately, researchers should aim for engagement with participants that moves beyond descriptive recording of events, people and places to a level of engagement that explores the "multifaceted complexities of the situation being studied, the intentions and motivations of the actors involved, and the context of the situation" (Marx, 2008, p. 795). The *active embodiment* of these practices, opposed to tokenistic use of the practices, is key and would add to inclusivity and quality.

In relation to this thesis, the application of an inclusive approach and the blueprint enhanced confidence that I had meaningfully and transparently captured accurate narratives of participant's experiences. This confidence, in turn, facilitated my ability to conduct a 'rich' analysis of the data, whereby data is interpreted and analysed with emphasis placed on describing context to support the analytic process (Marx, 2008). This compares with previous work that has explicitly avoided thick description for fear of overanalysing and losing the voice of people with intellectual disability in the analytical process (e.g., Brooker, Mutch, et al., 2015). The use of multiple contacts with participants, the multiple methods through which this data was collected, and my efforts to develop rapport with participants were key to this process.

The benefits of inclusive research also extend to overcoming ethical concerns about the inclusion and participation of people with intellectual disability in research, particularly those raised by ethics committees. Ethics committees are often concerned and may err on the side of paternalism when considering an individual's vulnerability to coercion and their ability to make informed decisions about their participation in research (Lai, Elliott, & Ouellette-Kuntz, 2006; McDonald & Kidney, 2012). Inclusive research, particularly an inclusive research approach, can assure ethics committees about the relevance of research topics and that participants are treated as active participants that demand respectful engagement rather than objects of research. It can also be used to counter paternalistic attitudes of ethics committees and demonstrate that not only is research involving people with intellectual disability essential, but also valid and beneficial. The clarity provided regarding the two distinct arms of inclusive research in this thesis can support ethics committees, researchers and participants to have an open discussion about inclusive research inclusive research approaches and inclusive research practices that can be used to improve the research.

8.4 Limitations of research

This thesis focused on people who had low support needs. Participants were mostly younger people who lived with family or had high levels of support from family; only two participants did not fit this description. Participants were recruited from physical activity and social support organisations and therefore were active and social individuals open to new social interactions. This recruitment may have overlooked people who faced barriers to being active or being social.

There was a large difference in the amount of contact I had with participants; some participants had two research contacts and others had over 10. For some participants, it was not possible to spend more time participating in the research while others did not want the research to end. This resulted in some participants having a ‘richer’ description than others; where the small amount of time spent with participants impacted on my ability to collect rich data, this was indicated in the participant’s vignette.

Additionally, initial contact about the research came from support people; this is a strategy preferred by ethics committees but brings with it some limitations (McDonald & Kidney, 2012). Participants are recruited through gate-keepers who have control over who they discuss the research with. Some individuals may not be approached about participating as the gate-keeper does not think they are eligible or would want to participate (Lennox et al., 2005). In this research, there was some confusion by gate-keepers about the benefits of participating; some indicated they were interested in the direct health benefits for the individual they supported. I discussed further the purpose of the research with these people which resulted in two individuals’ choosing not to participate.

As discussed in Chapter 5, the photovoice component of the research faced several challenges. Due to the open nature of the process (e.g., participants were not given photo limits or a strict timeframe in which to take the photos) a range of photos were taken across a long time period. Some participants did not remember why they had taken the photo and therefore did not want to discuss it. However, in these instances, the photos often provided insight in the participants' experiences and could be used as a conversation prompt. Potentially, more guidance and structure around photovoice may be needed but this must be balanced against the open, flexible and empowering nature of the process. Confines which are too restrictive may impact on the aim of photovoice to engage and capture participants' experiences (Wang & Burris, 1997). Additionally, participants mostly took photos of themselves and the people in their lives as well as other potentially identifiable features. The ethical considerations around sharing identifiable information elicited from photovoice by people with intellectual disability has been debated in the literature (Aldridge, 2007; Boxall & Ralph, 2009) with researchers often 'meeting in the middle' and sharing only photos that would not identify participants (Booth & Booth, 2003; Jurkowski, Rivera, & Hammel, 2009). This was an issue experienced in this research; although it was possible to blur out identifiable features, it was decided to err on the side of caution and not include the photographs to ensure participants' confidentiality.

8.5 Implications for practice and future research directions

The thesis has contributed to research in this field in ways that can be used in practice and to highlight future research directions. First, a qualitative research approach that emphasised the principles of inclusive research was developed. The blueprint presented in Chapter 4 provides a solid starting point for other researchers looking to conduct inclusive qualitative research with people with intellectual disability. Although the application of the blueprint and embodiment of the inclusive research approach was a positive and useful approach in the context of this research that added to the quality of the data collected, the blueprint can be further refined and developed in future research by reflecting on its utility.

Additionally, this thesis has made substantial contributions to enhancing current understandings of social support for people with intellectual disability. First and foremost, it acknowledges the complexity of social support experiences, not least due to the deep importance placed on social connection by people with intellectual disability, which may be at odds with the roles they play in the lives of the person with whom the relationship has been formed. This is particularly true in the context of relationships based on the premise of formal support whereby rules, social convention and individual preference may prevent the formation of reciprocal friendship. Another issue worthy of urgent attention is the poorly understood impact of loss of connection, and how social instability and changes to the social support environment can impact on individuals' self-conceptualisations as well as their perceptions of (formal) support itself. In sum, this thesis has contributed an understanding of the critical importance of social support in the lives of people with intellectual disability, as well as the potential impact lack of reciprocity or consistency can have on these lives.

Furthermore, this thesis has made a novel contribution to physical activity research with people with intellectual disability by taking a health practices perspective. This perspective was used as a framework to guide the research; it moved beyond the traditional perspectives taken in physical activity research to consider the social and individual contexts of participant's experiences. By acknowledging the context of participant's experiences, a more nuanced understanding of the relationship between physical activity and social support was developed and the use of this approach should be further explored in future research. This approach also highlighted the utility of the mechanisms proposed by Thoits (2011). These mechanisms are deserving of further investigation to understand the impact of social support on health practices for people with intellectual disability. Additionally, the nuances of companionship support require further unpacking in future research. For those supporting people with intellectual disability to participate in health practices, the tensions between meeting the preferences of the individual, particularly regarding emotional support, while also meeting their practical needs will need to be carefully managed. Some recommendations based on the findings of the thesis regarding key changes to social support that may support people with intellectual disability to be physically active include:

- Support people (in both informal and formal roles) and disability support organisations should consider the impact their views, attitudes and behaviours may impact on the behaviour of the individual they support and consider changing their views, attitudes and behaviours to create an environment supportive of healthy behaviours.
- Individuals can be supported to spend time with their friends doing incidental physical activity or a physical activity they both enjoy. For example, organising to go to a dance class with a friend.

- Utilising companionship support in physical activity; support people may be required for practical reasons but can also be a source of emotional support and encouragement for physical activity participation.
- The disability community with which an individual engages may be a source of social support for physical activity; seeking out physically active individuals, groups or organisations within the individual's personal community network could help to shape healthier social norms and link the individual with social network members who they can be active with in a disability friendly environment.

Finally, a key recommendation of this thesis is that future research should consider taking an inclusive approach to developing and implementing health promotion programs so as to be more reflective of the needs and experiences of people with intellectual disability.

8.6 Conclusion

The research presented in this thesis aimed to understand the role of social support in physical activity participation. In doing so, it also developed an understanding of social support for people with intellectual disability and developed a blueprint of inclusive research practices to guide qualitative research, which sought to support qualitative researchers to actively include and engage people with intellectual disability. Overall, the findings of this thesis emphasised the utility of using inclusive research practices to apply the key principles of inclusive research to the engagement of participants in research. This approach can improve the quality of research as well as the experiences of participants in line with the social model of disability. In contributing to an understanding of social support for people with intellectual disability, the thesis generated many questions deserving of further enquiry to further understanding this complex concept. Finally, the thesis proposes an alternative approach to developing health promotion initiatives for people with intellectual disability, one that embodies the key principles of inclusive research to meet the needs and consider the context of their experiences to produce sustained changes in behaviour.

Chapter 9 References

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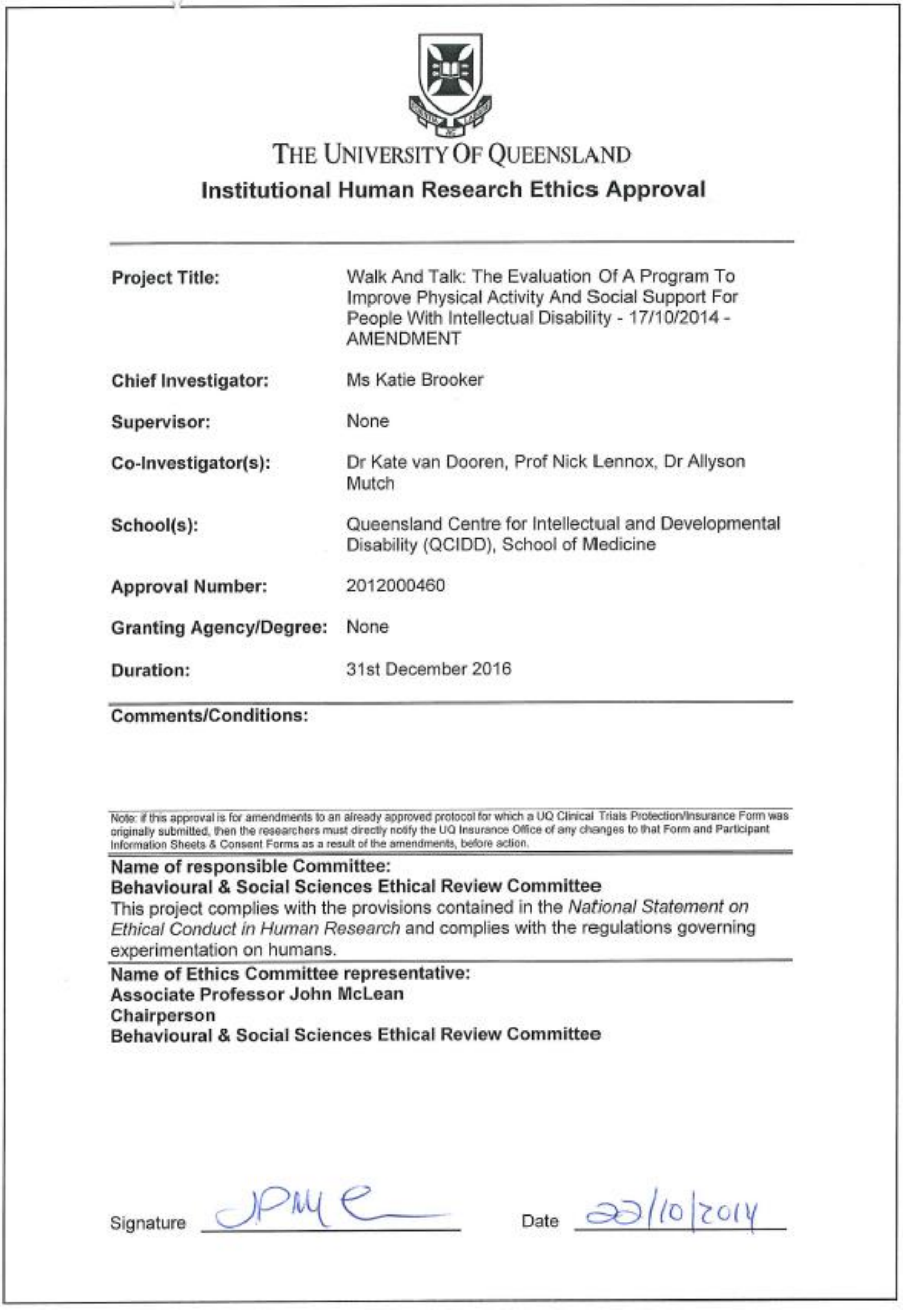
Chapter 10 Appendices

Appendix A:	**Ethical approval**
Appendix B:	**PRISMA checklist**
Appendix C:	**Terms of reference for advisory team**
Appendix D:	**Information sheet for families and support staff**
Appendix E:	**Participant information sheet**
Appendix F:	**Consent form**
Appendix G:	**Photovoice information sheet**
Appendix H:	**Withdrawal of consent form**
Appendix I:	**Ice-breaker tool**
Appendix J:	**Member checking tool**

Appendix A: Ethical approval



THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	Walk And Talk: The Evaluation Of A Program To Improve Physical Activity And Social Support For People With Intellectual Disability - 17/10/2014 - AMENDMENT
Chief Investigator:	Ms Katie Brooker
Supervisor:	None
Co-Investigator(s):	Dr Kate van Dooren, Prof Nick Lennox, Dr Allyson Mutch
School(s):	Queensland Centre for Intellectual and Developmental Disability (QCIDD), School of Medicine
Approval Number:	2012000460
Granting Agency/Degree:	None
Duration:	31st December 2016

Comments/Conditions:

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Associate Professor John McLean
Chairperson
Behavioural & Social Sciences Ethical Review Committee

Signature

Date 22/10/2014

Appendix B: PRISMA Checklist (Moher et al., 2009)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	NA
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	NA
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	43
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	43
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	NA
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	44
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	44
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	44
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	44
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	45
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	45
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	NA

Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	45
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NA
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	45-46
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	NA
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	NA
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	NA
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	NA
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	52-56
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	56
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	56-57
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	NA

Appendix C: Terms of reference for advisory team

Getting the picture: people with intellectual disability using photos to capture social support during physical activity

Terms of Reference for Advisory Team

My name is Katie Brooker.

I am studying at the Queensland Centre for Intellectual and Developmental Disability or QCIDD.

I am doing a project about people with intellectual disability and how people are active.

There are other people on the research team. Their names are Kate van Dooren, Allyson Mutch and Nick Lennox.

Kate, Allyson and Nick are researchers. Nick is also the director of QCIDD.

This document will tell you about the Advisory Team for my project.

It will explain about the Advisory Team and what you will be asked to do.

First I will explain what the project is about.

The name of the project is ‘Getting the picture: people with intellectual disability using photos to capture social support during physical activity’.

We are doing the project to find out about how people are active. We are interested in the kind of help or support people get to be active.

When we talk about being active we are talking about physical activity or exercise. There are lots of different types of physical activity or exercise. Some are walking, swimming, riding a bike, playing football or other sports.

The project has three parts.

- Part one is about talking.
- Part two is about taking photos.
- Part three is about going for a walk or exercise together and talking.

Part one: Talking. This part of the project means people will meet with Katie a few times. They will talk about being active, how they feel about being active and people who help them be active.

Part two: Taking photos. This part of the project is about taking photos of being active and sharing them with Katie. Katie and the people in the project will meet up to talk about the photos.

Part three: Exercise and talking. This part of the project is about Katie seeing how people are active. Katie will go with them on a physical activity they chose. If a person doesn't do any active, Katie and the person might go for a walk together. Katie might also ask some questions while they are being active.

The next part will tell you what the Advisory Team is about.

What is the Advisory Team?

- Members of the Advisory Team will **provide support and feedback** to Katie about her project.
- This might involve checking things are clear and easy to understand, that Katie is working in a respectful way and helping Katie to understand the results.

How will the Advisory Team meet?

- You can meet with Katie with other members of the Advisory Team or on your own.
- You can choose the **time and place** where we meet.
- I can visit you at your **home** or we can meet **somewhere else**.
- You can bring a **support person** if you want.
- Katie will meet with members of the Advisory Team about 6 or 7 times during her project.

What will I do on the Advisory Team?

Katie has a list of things that she will talk about with members of the Advisory Team.

They are:

- Checking the research plan is okay
- Checking the consent forms and information sheets are okay
- Questions to ask in interviews
- Questions to ask about photos
- Questions to ask about while exercising
- Any questions Katie has about collecting her research
- Talking about the results
- Talking about what's the best way to give the results to participants
- Talking about ideas of photo exhibit at the end of the project

You are welcome to add other things to talk about to the list.

What will Katie do on the Advisory Team?

- Katie will organise time with members that suit you and with enough notice.
- Katie will send out information about what we will talk about before meetings. This way you can have a think about it before the meeting.
- Katie will be respectful about your ideas and opinions. Your feedback is important and I will do my best to follow it.

What do I do if I have a question or want to know more?

You can phone Katie on 3163 2496 to talk about being on the Advisory Team. You can also email Katie at k.brooker1@uq.edu.au. Or you can ask your family or a support person to do this for you.

If you are not happy with the way Katie is working, you can phone the University on 3365 3924 and talk to the Ethics Officer. Or you can ask your family or a support person to do this for you. The Ethics Officer is a person who you can talk to about Katie or her project if you are not happy with the way Katie is working.

If you change your mind you can stop being on the Advisory Team at any time.

I will be okay with this ☺

Consent to Advisory Team

Getting the Picture: people with intellectual disability using photos to capture social support during physical activity

My name is ____

- I am happy to talk to Katie Brooker about her project.
- I agree that Katie can visit me at my home or another place that we agree on.
- I can bring a support person or family member when I meet Katie if I want to.
- I am happy for Katie to use a voice recorder during our talks.
- I am happy for Katie to talk to the research team about what I say.
- I know what I tell Katie will be kept private and Katie will not use my real name when talking about the project.
- I can decide if I want to be in Katie's research. I don't have to be in the research and I can stop at any time. It is my choice.

Signature: ____
Date: ____

Witness Signature: ____
Relationship to Participant: ____
Date: ____

Appendix D: Information sheet for families and support staff

QCIDD
Queensland Centre for Intellectual & Developmental Disability

THE UNIVERSITY OF QUEENSLAND
AUSTRALIA

Information Sheet for Families and Support Staff

Getting the picture: people with intellectual disability using photos to capture social support during physical activity

My name is Katie Brooker. I am studying at The University of Queensland. I am doing a project about people with intellectual disability and how people are active.

________________ has been invited to participate in this project.

There are other people helping me with this project. Their names are Kate van Dooren, Allyson Mutch and Nick Lennox. Kate, Allyson and Nick are researchers. Nick is also the director of the Queensland Centre for Intellectual and Developmental Disability.

This Information Sheet tells you about the project. It explains the processes involved with taking part. Knowing what is involved will help you support ________________ to decide if he/she wants to take part in the project. We have recommended to ________________ that before deciding whether or not to take part he/she talks about his/her participation with a relative, friend or support worker.

What is the purpose of this project?

The purpose of this project is to gain an understanding of the relationship between social support and physical activity for people with intellectual disability. We are interested in this because many people with intellectual disability do not meet the physical activity guidelines and also experience a lack of social support. Previous research has found people with intellectual disability identify having a person to be active as a facilitator and not having a person to be active with as a barrier. Despite this evidence there have been few efforts from researchers in the health promotion and disability fields to understand and increase physical activity and social support among adults with intellectual disability. We will use what we learn to inform future interventions to improve health.

What does participation in this project involve?

If _______________ decides to take part in the project, he/she will first meet with the researcher, Katie Brooker, to talk about the project. Meeting with Katie will take approximately 30 minutes to an hour. He/she can bring a family member or support person along to the meeting. He/she is also are able to decide on a time and place convenient to him/her. He/she can take a break or stop the meeting at any time.

He/she will then be required to sign the Consent Form before he/she can participate in the project.

There are three parts to this project; talking, taking photos, and exercising and talking. Each part is optional and _______________ may participate in some or all parts of the project.

Talking (interviews)

Katie will meet with _______________ several times over a few months to talk. We ask to meet multiple times over time so that we can gain a deeper understanding of the topic. Katie will ask _______________ questions about physical activity, when he/she is active, how he/she feels about physical activity, how he/she feels about being active with another person, what he/she does and doesn't like about physical activity and other things about physical activity he/she may wish to talk about.

The aim of the interviews is to understand how people view physical activity, to understand the meaning of social support in regard to physical activity for people with intellectual disability and if this is different for people who receive formal or informal support.

Taking photos (photovoice)

Katie will meet with _______________ and ask him/her to take photos about a time when he/she is active, what things stop him/her from being active and things that help him/her to be active. If _______________ doesn't have access to a camera we have cameras that he/she can borrow. He/she will be able to choose what he/she takes photos of. When he/she is finished taking photos, a timeframe will be decided upon between Katie and _______________, Katie will either print the photos or display them on a computer (_______________ will chose). We will then talk about the photos.

The aim of photovoice is to identify the barriers and facilitators people face to being active and to further understand the relationship between physical activity and social support.

Exercising and talking

Katie will meet _______________ to participate in physical activity. The physical activity will be chosen by _______________ and can be a regular activity or a one-off/new activity. If _______________ does not to do any activity, Katie will meet with him/her to discuss similar topics as they would have done if he/she did an activity. Katie will ask questions either during or after the activity (_______________ will chose) about why he/she likes the activity, things that stop him/her from doing the activity, things that help him/her to do the activity and who he/she usually does the activity with.

The aim of this part of the project is to observe participants' process of being active; we want to learn and see things that might not be obvious, brought up in discussion or the participant is aware of. We also want to experience the local environment with which participants engage (as it may be different to our usual experience) and so we can experience what the participant has described to us in its context. It also may increase participant's awareness of barriers and facilitators that he/she may only think of while doing their physical activity.

Depending on the number of parts of the project _______________ participates in his/her involvement may range from a month to three months. The entire project is expected to take six months. During all parts of the project _______________ may chose if he/she brings a family member or support person with him/her. He/she is also are able to decide on a time and place convenient to him/her and he/she can take a break or stop at any time. A voice recorder will be used to record the meetings; if he/she does not want to be voice recorded Katie will take hand written notes either during or after the meetings.

Does _______________ have to participate in this project?

Participation in any research project is voluntary. If _______________ does not wish to take part, he/she does not have to. If he/she decides to take part and later changes his/her mind, he/she is free to withdraw from the project at any stage. If he/she does decide to take part, he/she will be given his/her Information Sheet and Consent Form to sign and he/she will be given a copy to keep. His/her decision whether to take part or not to take part, or to take part and then withdraw, will not affect his/her relationship with UQ or QCIDD.

What if _______________ wants to withdraw from the project?

If _______________ does consent to participate, he/she may withdraw at any time. If he/she decides to withdraw from the project, please notify a member of the research team before withdrawing (this can be done by the participant, a family member or support person). If _______________ does withdraw, he/she will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided by the research team. When signing the 'Withdrawal of Consent' form he/she will be asked if he/she wants the data already collected from him/her to be included in the research or not.

What are the possible benefits and risks of taking part?

We cannot guarantee or promise that _______________ will receive any personal benefits from this research. Possible benefits may include contributing to research about physical activity and social support for adult's intellectual disability. We do not see any risks to participating in this research.

What will happen to information the researchers collect?

Any information obtained in connection with this project will remain confidential. Participants will be assigned a participant number so that names are not recorded on hard- or electronic-copy notes and transcripts. Hard-copy notes and digital recordings will be stored in a lockable filing cabinet in the QCIDD office. All analyses and transcripts will be de-identified and password protected. Information will only be used for the purpose of this research project and it will only be disclosed with _______________ permission.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that _______________ cannot be identified.

Who has reviewed the research project?

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines. You free to discuss this study with project staff (Katie Brooker, tel: 3163 2496, email: k.brooker1@uq.edu.au). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 07 3365 3924.

Who can I ask if I have question?

You can contact Katie Brooker. You can call her (3163 2496) or email (k.brooker1@uq.edu.au)

Appendix E: Participant information sheet

QCIDD
Queensland Centre for Intellectual & Developmental Disability

THE UNIVERSITY OF QUEENSLAND
AUSTRALIA

Invitation to

Getting the picture: people with intellectual disability using photos to capture social support during physical activity

Hello, how are you?

My name is Katie Brooker.

I am studying at the Queensland Centre for Intellectual and Developmental Disability or QCIDD

I am doing a project about people with intellectual disability and how people are active.

There are other people helping me with this project. Their names are Kate van Dooren, Allyson Mutch and Nick Lennox.

Kate, Allyson and Nick are researchers. Nick is also the director of the Queensland Centre for Intellectual and Developmental Disability.

We would like to know more about you and how you are active.

We want to know about how you are active and who you are active with so that we can help people to be more active.

When we say active we are talking about when you do physical activity or exercise. There are lots of different types of physical activity or exercise. Some are walking, swimming, dancing, riding a bike, playing football or other sports.

The project has three parts.

- Part one is about talking.
- Part two is about taking photos.
- Part three is about doing exercise together and talking.

You can take some time to decide if you want to be part of the project. You can talk to someone in your family, friends or a support worker about being part of this project.

Katie will give you another information sheet to share with your family, friends or support worker that will tell them about this project.

You can be in some parts or all parts of the project.

You can choose to not be part of this project. It is up to you.

Your part in the project should only take a few months to do.

This is what could happen.

You and I can meet each other

- I will tell you about my project.
- You can ask me any questions.
- You can choose the place where we meet.
- I can visit you at your home or we can meet somewhere else.
- You can bring a support person if you want.
- You can choose if you want to be in my project.

What will happen if you want to be in my project?

There are three things that can happen.

- I will come to talk to you about exercise.
- I will give you a camera to take photos about exercise.
- I will do exercise with you. I will also talk to you about it.

You can be in some parts or all parts of the project.

Telling your story and sharing your photos can help me learn about how people with intellectual disability are active.

Part one – Talking

You and I will meet to talk a few times

- I can visit you at home or we can agree to meet somewhere else.
- The meeting will take between 30 minutes and 1 hour, or until you want to stop.
- We can take a break during our talk if you want to.
- You can bring a support person or family member if you want to.
- We will meet a few times to talk.
- This might happen over a few months.

I will talk to you about

- When you are active. Like when you go for a walk or exercise.
- How you feel about being active.
- How you feel about being active with another person.
- People who help or support you to be active.
- What you like or don't like about being active.
- Other things about being active that you want to talk about.

Part two – Taking photos

You and I will meet to talk about taking photos

- I can visit you at your home or we can agree to meet somewhere else.
- The meeting will take between 15 minutes and 30 minutes, or until you want to stop.
- We can take a break during our talk if you want to.
- You can bring a support person or family member if you want to.
- I will give you a camera. You can use your own camera if you like.
- I will talk to you about why I want you to take photos.

You will take some photos

- You can decide what you take photos of.
- When you are finished taking photos I will come and get the camera.
- I will print the photos off or show them to you on a computer.
- We will meet up to talk about the photos.
- I can visit you at your home or we can agree to meet somewhere else.
- The meeting will take between 30 minutes and 1 hour, or until you want to stop.
- You can bring a support person or family member if you want to.

Part three – Exercise and talking

You and I can meet to go for some exercise

- I would like to see how you normally go for a walk or exercise. It doesn't have to be walking. It could be any physical activity you enjoy.
- I would like to talk to you while we exercise. But we don't have too.
- I can visit you at your home, where you usually exercise or we can agree to meet somewhere else.
- The exercise can go for the normal time you would do it, or I can do it until you want to stop.
- We can take a break during our exercise if you want to.
- You can bring a support person or family member if you want to.

I would like to talk to you about your exercise

- We can talk while we exercise.
- We can talk after the exercise.
- We don't have to talk much while we exercise. It is up to you.

I will talk to you about

- Why you like exercise.
- Things that stop you from exercising.
- Things that help you to exercise.
- Who you usually exercise with.

If you say it is okay, I will use a voice recorder to record our talks and I will write things down. This will help me remember what we talk about.

I will keep what you say private.

- I will not use your real name when I write about my work. I will not use the names of any people or services you talk about.
- I will keep my notes and voice recorder in a locked filing cabinet in my office.

I will tell other people what I have learned about how people with intellectual disability are active

- I will talk about my project at conferences and meetings.
- I will write about my project in my thesis and in articles.
- I will not use your real name when I talk or write about my research.

I will send you a copy of the results of the project. I will do this when I have finished doing the research. It might take six months to do.

There may be some benefits or risks to being part of this project.

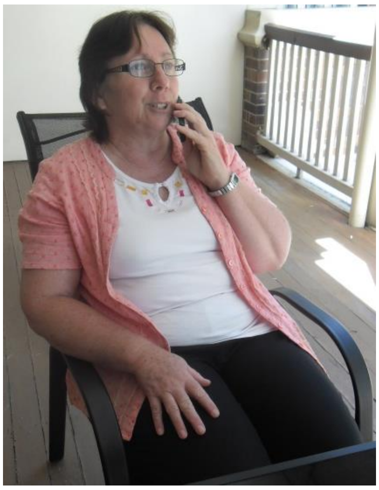
- Your story will help us to help other people with intellectual disability to be active and healthy
- We do not think there are any risks to being part of this project.

People at The University of Queensland have looked at this project and said it is okay to do. These people are from an ethics review board and their job is to make sure projects are safe.

If you change your mind and don't want to be in the project anymore, that's okay.

- You will need to sign a form to say you don't want to be part of the project anymore.
- We will ask you if you want us to include what you have told us to be used in the project. It is okay to not want what you have told us to be used in the project.

What do I do now?



You can phone me on 3163 2496 to talk about your part in my work. Or you can ask your family or a support person to do this for you.

If you do not want to talk to me you do not have to do anything.

If you are not happy with the way I am working, you can phone the University on 3365 3924 and talk to the Ethics Officer. Or you can ask your family or a support person to do this for you. The Ethics Officer is a person who you can talk to about Katie or her project if you are not happy with the way Katie is working.

If you change your mind you can stop being in my research at any time.

I will be okay with this ☺

Appendix F: Consent form

Consent to

Getting the Picture: people with intellectual disability using photos to capture social support during physical activity

My name is ____

- I am happy to talk to Katie Brooker about being active.
- I agree that Katie can visit me at my home or another place that we agree on.
- I can bring a support person or family member when I meet Katie if I want to.
- I am happy for Katie to use a voice recorder during our talks.
- Katie may also like to talk to my parent or guardian and support worker at another time.
- I know what I tell Katie and my photos will be kept private and Katie will not use my real name when talking about the project.
- I can decide if I want to be in Katie's research. I don't have to be in the research and I can stop at any time. It is my choice.
- If I decide to stop being in Katie's research, I can decide if what I have told Katie will be used in her project.

☐ I am happy to take photos about being active for Katie. I am happy to share my photos with Katie and talk to Katie about my photos. (Please tick if you agree)

☐ I am happy to go for a walk or exercise with Katie. (Please tick if you agree)

Signature: ____
Date: ____

Witness Signature: ____
Relationship to Participant: ______________________________________
Date: ____

Appendix G: Photovoice information sheet

QCIDD
Queensland Centre for Intellectual & Developmental Disability

THE UNIVERSITY OF QUEENSLAND
AUSTRALIA

About Photovoice for

Getting the picture: people with intellectual disability using photos to capture social support during physical activity

We are doing this project to find out about how people are active. We are interested in the kind of help or support people have to be active.

This part of the project is called **photovoice**.

Photovoice is when people take photos about a topic. They then share the photos with the research team and have a chat about them.

This is what could happen.

You and I will meet to talk

- I can visit you at home or we can agree to meet somewhere else.
- The meeting will take between 15 minutes and 30 minutes, or until you want to stop.
- We can take a break during our talk if you want to.
- You can bring a support person or family member if you want to.

I will talk to you about

- Why I want you to take photos.
- What kind of things I want you to take photos of.
- What I will do with the photos when we are finished.

What I will ask you to take photos of

- Things that stop you from being active.
- Things that help you to be active.
- A time when you are active.

About the camera

- You can use your own camera. It can be a camera on a phone.
- If you don't have a camera I can give you a camera to borrow.
- If you use Katie's camera, she will show you how to use it.
- Once the photovoice part of the project is over you will have to give the camera back.

Things to remember when taking photos

- It is okay to take photos of places and things.
- We ask that you don't take photos of people you don't know.
- You get to decide what things you take a photo of.
- You can keep a record of when you take photos. This might be a good idea if you take lots of photos of different things. Or you can ask your family or a support person to do this for you. This will help you when you talk to Katie about the photos.

When you are finished taking photos

- I will come and get the camera.
- I will print the photos off or show them to you on a computer. You can choose what you would like.

We will meet up to talk about the photos.

- I can visit you at home or we can agree to meet somewhere else.
- The meeting will take between 30 minutes and 1 hour, or until you want to stop.
- We can take a break during our talk if you want to.
- You can bring a support person or family member if you want to.
- I will ask you questions about the photos. I'm interested in why you took the photos.

Telling your story and sharing your photos can help me learn about the how people with intellectual disability be active.

If you say it is okay, I will use a voice recorder to record our talks and I will write things down. This will help me remember what we talk about.

You will get to keep a copy of the photos. I can print the photos for you or you can have a digital copy on a CD. I will also keep a copy of the photos. I will not show them to other people unless you say it is okay to.

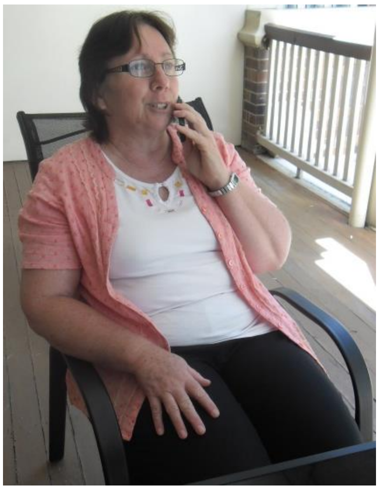
I will keep what you say private.

- I will not use your real name when I write about my work. I will not use the names of any people or services you talk about.
- I will keep the photos, my notes and voice recorder in a locked filing cabinet in my office.

I will tell other people what I have learned about how people with intellectual disability are active

- I will talk about my project at conferences and meetings.
- I will write about my project in my thesis and in articles.
- I will not use your real name when I talk or write about my research.
- I will not show your photos to other people unless you tell me it is okay.

What do I do if I have questions?



You can phone me on 3163 2496 to talk about your part in my work.

If you are not happy with the way I am working, you can phone the University on 3365 3924 and talk to the Ethics Officer. Or you can ask your family or a support person to do this for you. The Ethics Officer is a person who you can talk to about Katie or her project if you are not happy with the way Katie is working.

If you change your mind you can stop being in my research at any time.

I will be okay with this ☺

Appendix H: Withdrawal of consent form

Withdrawal of Consent to

Getting the picture: people with intellectual disability using photos to capture social support during physical activity

My name is ____

I do not want to be involved in this project anymore.

Please circle:

I want what I have told Katie so far to be used in the project.

I do not want what I have told Katie to be used in the project.

Signature: ____

Date: ____

Witness Signature: ____

Relationship to participant: ____

Date: ____

<u>Research Team Only:</u>

I have explained what it means to withdrawal from the project and the participant has understood.

Researcher: ____

Signature: ____

Date: ____

Notes: ____

____

____

Appendix I: Ice-breaker tool

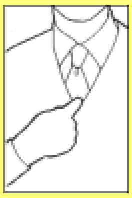
Hello!
Nice to meet you!

My name is Katie

Today

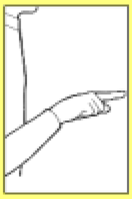
Let's have a chat and get to know each other

About Me



and

About You



I like

Taking Molly for a walk with her friends

Chocolate

Gardening

Sewing

Things I don't like

Cheese

Smoking

Rude
People

My work

Going to meetings

Talking to people about their health

Writing about what I do

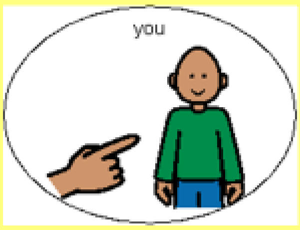
Do you want to ask me anything?

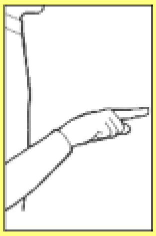
?

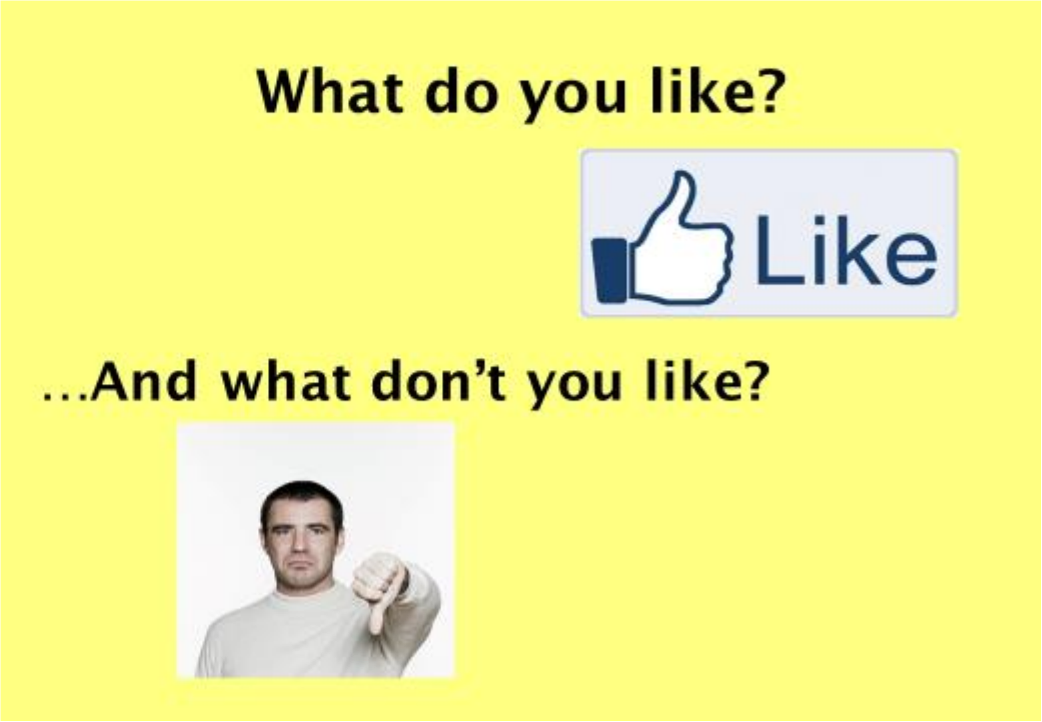
YES **NO**

Now that you know about me…

I'd love to hear about you!







What do you like?

…And what don’t you like?

Appendix J: Member checking tool

Checking what we talked about last time

Katie and I check what we talked about last time

We check that Katie got it right

Agree on what we are going to talk about today

Katie and I check the topics we decided on last time

Katie and I add other topics we want to talk about today

Katie and I change today's list of topics, if we need to

Doing the talking

Katie and I do the talking together

Deciding what to talk about next time

Katie and I decide on what to talk about next time

Katie working on the information afterwards

Katie takes the information away to work on it