A Life Worth Smiling About: Experiences of Young People with Neuromuscular Disease Participating in the Duke of Edinburgh’s Award

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KEYWORDS

Participation
Disability
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Intervention
ABSTRACT

For a variety of reasons, the daily life experiences of young people living with neuromuscular disease are typically modified to a level that is potentially disengaging. This study explored the experiences of eight young people with neuromuscular disease and their eight parental caregivers participating in the well-known Duke of Edinburgh’s Award, offered though a community support organisation, the Muscular Dystrophy Association New South Wales. This program encourages young people to experience challenge, adventure and gain new skills and has, thus far, never been available to persons with a neuromuscular disease.

Semi-structured interviews, conducted with each young person-parental caregiver dyad, were recorded and transcribed verbatim before being analysed using principles of constructivist grounded theory methodology. Participants, called Dukies, and their parents described their initial motivations for enrolling in the Award, including the opportunity for the Dukies to engage in the community and participate in new activities and learn new skills. They also reported a number of outcomes for the Dukie including: a new outlook and purpose in life, increased self-belief, independence, and social confidence. Parents described learning to ‘let go’ and having quality time for themselves and other family members. A number of essential ingredients enhanced participation for the Dukies including: choice, challenge and access to resources and supports for parents.

The Duke of Edinburgh’s Award is an example of an intervention resulting in increased participation for children and young people with neuromuscular disease, who are expected to fulfil the same criteria as able-bodied peers. Findings of the current study will inform development of community-based programs and serve to advocate for programs with similar philosophies to be developed.
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DECLARATION

I, MARIAM FARID, hereby declare that the work contained within this thesis is my own and therefore, to the best of my knowledge and belief, original, except as acknowledged within the text. I declare that I have not submitted this material, either in whole or in part, for a degree at this or any other institution.

I, MARIAM FARID, declare that I was the principle researcher of all work included in this thesis. In addition, ethical approval from The University of Sydney Human Research Ethics Committee was granted for the study presented in this thesis. Participants were required to read a participant information document and written informed consent was gained prior to data collection.

Name: Mariam Farid

Signature Date: 05th January 2017
EDITING CERTIFICATION

In accordance with the University of Sydney policy on thesis editing, editorial assistance was sought in the final production of this thesis. The editor provided proof reading, copy editing and formatting. The editor employed was: Margaret A. Short

Margaret A. Short, Ph.D., OT, D.Min. FAOTA
Research and Editorial Consultant
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To my research participants, sharing your life stories and welcoming me into your homes is a significant gift to me; and I hope my work expresses my gratitude.
DEDICATION

Dedicated to my parents Ghulam and Ramzia, thank you for making the biggest sacrifice of leaving your family, your home and your country in order for your children to have an education and a better life. I am forever thankful.
CHAPTER ONE - INTRODUCTION

Neuromuscular Disease

Neuromuscular disease refers to a group of genetic and degenerative disorders which affect the peripheral nervous system resulting in disablement (Emery, 1991). The World Health Organisation (WHO) classifies disablement as impairment, disability and disadvantage. In the case of neuromuscular diseases, impairment includes progressive weakness, spine deformities, joint contractures, pain, decreased cardiopulmonary function and, in a very small percentage intellectual impairment (Boyer, Drame, Morrone, & Novella, 2006; McDonald, 2002). These impairments result in decreased functioning in activities of daily living, impaired psychosocial adjustment and decreased mobility (Abresch, Seyden, & Wineinger, 1998; Mah, Thannhauser, Kolski, & Dewey, 2008; McDonald, 2002). Despite these impairments, advances in the medical and allied health management have resulted in an increase in the life expectancy of children and young people diagnosed with a neuromuscular disease (Hermans et al., 2010). As a result of this increase in children’s life expectancy, health professionals and other stakeholders looking after these children are now even more obliged to advocate for better quality of life and participation opportunities for children and young people with neuromuscular disease.

The diagnosis of neuromuscular disease not only impacts the individual diagnosed with the condition but also their parents, siblings and extended family (Heiman, 2002; Mah, Thannhauser, McNeil, & Dewey, 2008; Pangalila et al., 2012). Families gradually accept the condition and make changes to accommodate their child’s disease (Mah, Thannhauser, Kolski, et al., 2008; Wallander & Varni, 1998). In addition, parents take on extra responsibilities, becoming their child’s caregiver and advocate (Mah, Thannhauser, McNeil, et al., 2008).

Increased Life Expectancy in Neuromuscular Disease
In the absence of any curative treatment, a medical approach has been adopted with a focus on extending life expectancy. Advances in medical management, rehabilitative care and technology have increased life expectancy considerably. This has led to a growing population of adults with neuromuscular diseases who are limited in their physical functioning and dependent on their families for care (Bushby et al., 2005; Kohler et al., 2009; Pangalila et al., 2012).

Providing care for a severely disabled family member can be burdensome and can lead to stress, depression, social isolation, and overall deterioration in family members’ quality of life (Brouwer, van Exel, van den Berg, van den Bos, & Koopmanschap, 2005; Mah, Thannhauser, McNeil, et al., 2008). This has been reported in the neuromuscular literature (Daoud, Dooley, & Gordon, 2004). Despite the burden of care, parents report deep enrichment to their lives and rewarding experiences which they cannot imagine living without (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Pangalila et al., 2012). However, the caring role is complex. In their role as the caregiver, parents can overprotect their children, thereby creating dependency; this is evident in historical and more recent research (Buchanan, LaBarbera, Roelofs, & Olson, 1984; Heah, Case, McGuire, & Law, 2007; Segrin, Woszdlo, Givertz, & Montgomery, 2013). Parental overprotection in adolescence or adulthood can be a barrier to participation opportunities, normal for their age group.

As a paediatric social worker, in a busy neuromuscular service in a major tertiary paediatric hospital, I have observed the multifaceted barriers to participation, experienced by children and young people with neuromuscular diseases. These barriers include the physical and social environment, and family and individual factors. Despite attempts at addressing some of these barriers, optimal participation remains a challenge for young people with
neuromuscular diseases. This is concerning, particularly for the emerging population of young adults.

**Quality of Life Approach to Neuromuscular Disease**

Increased life expectancy for young people with neuromuscular diseases has resulted in young adults with high physical care needs whose psychological needs are similar to that of their healthy peers. Therefore, the role of medicine and allied health is to adopt quality of life and participation as an important outcome measure.

The impact of neuromuscular disease on quality of life and participation is well described in the literature (Abresch et al., 1998; Baiardini et al., 2011; Bendixen, Senesac, Lott, & Vandenborne, 2012; Bray, Bundy, Ryan, North, & Everett, 2010; Ozer, Yildirim, Yilmaz, Duger, & Yilmaz, 2010). Bray and colleagues highlighted the importance of participation for boys diagnosed with Duchenne muscular dystrophy that were maturing cognitively and psychologically but deteriorating physically (Bray, Bundy, Ryan, North, & Burns, 2011; Bray, Bundy, et al., 2010; Bray, Burns, Morrison, & Bundy, 2010). In another study, Bendixen and colleagues (2012) compared participation in life activities and perceived quality of life between boys with Duchenne muscular dystrophy (n= 50) and an aged matched population of unaffected boys (n=25). In this study it was evident that participation was impaired for boys with Duchenne muscular dystrophy. Not surprisingly, boys with Duchenne muscular dystrophy were found to have significantly lower participation in physical activities compared to unaffected boys (Bendixen et al., 2012). Further, the amount of time boys engaged in an activity and participated in social activities declined with age. Activities of choice were less physical. The decline in participation for the older boys is likely to be related to a number of factors. These include personal factors such as the progression of their disease, which involves declined mobility and lack of motivation or societal barriers such as
social isolation and environmental barriers (Bendixen et al., 2012). Both of these studies have reported poor rates of social engagement in boys with Duchenne muscular dystrophy.

Participation is not well understood for individuals diagnosed with neuromuscular disease, and there is a lack of intervention models that can guide intervention (Bendixen, Lott, Senesac, Mathur, & Vandenborne, 2014). While the link between intervention and increased participation is still in its infancy for the neuromuscular disease population, other disease groups such as cerebral palsy are far more advanced in their description. Therefore, there is a need for a better understanding about what meaningful participation looks like for the neuromuscular disease.

**Intervention Aimed at Increasing Participation and Improving Quality Of Life**

In response to the lack of participation-based programs for individuals with a neuromuscular disease, the Muscular Dystrophy Association New South Wales (MDNSW) designed an innovative program. This program was designed to improve participation for young people with neuromuscular disease through ensuring access for its members to the well-known Duke of Edinburgh’s Award. The goal of this program is to improve quality of life by reducing social isolation, enhance motivation and self-esteem and promote increased community participation. The Duke of Edinburgh’s Award is an internationally recognised program, which invites young people from all around the globe to participate in activities and to experience great achievement and results. The Award program began in the United Kingdom in 1956 as the Duke of Edinburgh’s Award. The aim of the program was to motivate young boys to become involved in a balanced program involving voluntary and self-development activities during the tough period of adolescence. Two years later, a girls’ scheme was developed in 1958; and in 1969 the two separate schemes were merged into one Award.
The flexibility of the Award made it easy to modify and integrate into different cultures and societies. As a result, the Award is now a well-recognised program on an international scale and used by schools and organisations working with young people throughout the world. However, the program has only limited access for people with disability.

MDNSW is a non-for profit organization, which advocates for and supports individuals living with a neuromuscular disease and their families. Their mission is to improve the quality of life for all people living with a neuromuscular disease.

MDNSW is the first disability service provider in Australia to become a National Licensed Operator of The Duke of Edinburgh’s Award. Dedicated staff at MDNSW were driven to commence the program in order to provide an experience that encouraged self-directed learning and development for young people diagnosed with a neuromuscular disease. With financial support from Ageing Disability and Home Care, an organisation part of the Department of Family and Community Services (funded by local government), the program was established in May 2011. Similar to the international Duke of Edinburgh’s Award, young people aged between 14 to 25 years are invited to participate in a non-competitive program of self-directed activities. Participants also known as Dukies can choose to do their Bronze, Silver or Gold Awards. The Dukies commence on the Bronze Award and upon completion they progress through to the next level. Each level requires the young person to undertake an activity of their own choice in each of the four sections of skill, fitness, volunteering, and adventurous journey. The Dukies participate on a regular basis over a set period of time for each section and take ownership of as much of the planning, decision-making and record keeping as possible.

At commencement of my research study, ten Dukies had been enrolled in the Award through MDNSW. The statistics for the Award in May 2016 were:
• 42 young people with neuromuscular conditions have participated in MDNSW’s Duke of Edinburgh’s program since it began in 2011

• 20 Dukies have completed the Bronze level

• 7 Dukies have completed the Silver level

• 2 have completed their Gold level

• Currently 13 Dukies are enrolled in an Award

**Aims of this Research**

The aims of the current study were to:

• Explore the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award

• Explore the experiences of parents whose child was participating in the Duke of Edinburgh’s Award

In line with these aims, I conducted qualitative research interviews with eight young people with neuromuscular disease who were participating in the Duke of Edinburgh’s Award. Interviews with the young person (or Dukies) focused on their experience of participating in the Duke of Edinburgh’s Award and its impact on their lives. Interviews with primary caregivers who will be referred to as ‘parents’ throughout this thesis focused on their views about the impact of the Duke of Edinburgh’s Award on their child and their experience of their child’s participation in the Award.

Insight into the experiences of the young people enrolled in the Award as well as the experiences of their parents was hoped to provide important information about if, and how, the program impacted participation. Overall, this thesis provides scope to learn about optimal participation for people with disabilities from a group of young people with neuromuscular disease. The findings will benefit not only young people with neuromuscular disease but
more broadly individuals with disabilities. Some of the significant outcomes of this research include: a conceptually informed model of participation - ‘optimal participation’ and understanding how young people with disabilities could be engaged in activities.

Taken together, the conceptualisation and empirical work conducted in this study are proposed to benefit disability organisations, health professionals and researchers by providing a rich description of participation in a widely available program for young people with disabilities. With this insight it is hoped researchers will be in a better position to study participation and quality of life for young people with neuromuscular disease. Furthermore, these individuals will be better equipped to promote participation for young people with disabilities.

Outline of the Thesis

Chapter 1- Introduction: current chapter, orients the reader to the thesis and sets the scene by providing background for the research project

Chapter 2- Literature review: an extensive review of literature and theory on participation for children and young people with neuromuscular disease and disability is presented. This chapter also highlights the deficiencies in current conceptualisation of participation.

Chapter 3- Methodology and methods: comprehensively describes the recruitment process and the qualitative methodology used to collect and rigorously analyse data

Chapter 4- Results: details the main findings of the qualitative data interviews with Dukies and their parents with a focus on their experiences of the Duke of Edinburgh’s Award

Chapter 5- Discussion: discusses the main findings of the thesis, provides commentary on the implications of the findings presented in the thesis, and suggests future directions

Chapter 6- References
Chapter 7- Appendices
CHAPTER TWO - LITERATURE REVIEW

This chapter provides a critical synthesis of the literature regarding participation for children and young people with disabilities. A definition of participation is stated, followed by a review of participation for children and young people with disabilities. For the purposes of this review, the term “children or child” will be used to ensure consistency. This is reflective of the volume of participation literature focusing on children with disabilities. Where there is relevant literature in young people, this will be elucidated. The dimensions and determinants of optimal participation and an outline of measurement of participation and intervention models of participation are then synthesised. The chapter concludes with a critical review of self-engagement, reported to be a key ingredient of participation.

Definition of Participation

Participation has been studied and described in many different health disciplines, and there is no accepted single definition. Participation originates from the Latin word *particeps* which means part-taking, and *pars + capere* which means to take part in or to share in (Law, 2002). In the English language, participation has been defined as involvement or part taking in an activity, and having common interests with others (Stevenson, 2010). Participation is defined by the International Classification of Functioning (ICF) as “involvement in life situations” (WHO, 2001, p. 229). Participation is categorised into major life areas such as work and school, social, community and civil life (WHO, 2001). The ICF definition of participation is the most cited and universally accepted definition.

Importance of Participation

Participation is a human right (Hendricks, 2007). Participation impacts an individual’s quality of life and is crucial for human development (Larson & Verma, 1999; Law, 2002; Mahoney, Harris, & Eccles, 2006). The benefits of participation across the lifespan have been
widely reported (Garton & Pratt, 1991; Larson & Verma, 1999; Law et al., 2006; Masten & Coatsworth, 1998; Rutter, ., & et al., 1990; Stewart, Reid, & Mangham, 1997; Viemero & Krause, 1998).

Children and young peoples’ participation in everyday life is crucial for achieving life satisfaction and a sense of competence and purpose in life, all of which are essential for healthy psychological, social, emotional and skill development (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012; Law, 2002; Law et al., 2006). In typically developing children and young people, a strong relationship with a caring adult, a positive school experience, and participation in extracurricular activities can lead to resilience (Law, 2002). For children with a physical disability, participation in physical activities leads to improvement in function and strength (Auld & Johnston, 2014; Chen et al., 2012; Damiano, Dodd, & Taylor, 2002). Furthermore, for children and young people with neuromuscular conditions, engagement in social and self-improvement activities leads to deeper enjoyment of that particular activity and the formation of strong relationships (Bendixen et al., 2014).

Categories of Participation

Participation has been categorised by King and colleagues (2009) into formal and informal activities. This distinction is important, as both are considered to have different outcomes on an individual’s physical, social, emotional and community development (Beauvais, 2001). Formal activities are structured and involve a set of rules or goals and often have a designated leader, coach or instructor (Law et al., 2000). Formal activities include organised sports, clubs, groups, organisations and other skilled-based activities (King et al., 2009). Informal activities are spontaneous in nature and are often initiated by the individual themselves (Law et al., 2000). Informal activities include activities such as: hobbies, social activities, quiet recreation, entertainment, physical activities and chores (King et al., 2009).
The benefits of participation in formal, organised, out-of-school activities for typically developing children and young people are well documented (Badura, Geckova, Sigmundova, van Dijk, & Reijneveld, 2015; Denault & Poulin, 2016; Eccles, Barber, Stone, & Hunt, 2003; Larson et al., 2004; Larson, 2000; Mahoney et al., 2006; Mahoney, Larson, & Eccles, 2005; Roth & Brooks-Gunn, 2003; Sharp, Tucker, Baril, Van Gundy, & Rebellon, 2015). Organised activities are believed to be instrumental to a child or young person’s development due to a number of important benefits (King et al., 2009). These benefits include enhanced competencies, such as initiative (Larson, 2000); social skills, formation of identity and self-concept, and self-esteem (Beauvais, 2001; Eccles & Barber, 1999); self-efficacy and self-determination (Catalano, Berglund, Ryan, Lonczak, & Hawkins, 2004); and improved social, physical, academic, psychological and community outcomes (Mahoney et al., 2006; Mahoney et al., 2005).

Several studies have described participation of children and young people with disabilities in informal activities (Harding et al., 2009; King et al., 2009; Law et al., 2006; Majnemer et al., 2008). Children with disabilities participated in significantly fewer formal and informal activities and participated in these activities less intensely than children without disabilities (King et al., 2009). The consensus is that children with, and those without, disabilities enjoy informal activities more than formal activities (Harding et al., 2009; King et al., 2009; Law et al., 2006; Majnemer et al., 2008). Conversely, lower or average enjoyment of formal activities by children with disabilities is attributed to i) a lack of psychological engagement in the activity ii) lower activity choice and intrinsic motivation iii) lack of opportunities for meaningful experiences iv) lack of physical emotional support to encourage involvement (King et al., 2009).

**Participation for Children with Disabilities**
Children and young people with physical disabilities face ongoing challenges in their day-to-day life due to difficulties in mobility, communication, and socialisation as well as environmental barriers (Kang, Palisano, King, & Chiarello, 2014; King et al., 2009). As a result, the impact of disability and the consequent reduced participation in activities and social isolation are profound (Bendixen et al., 2012; Bult, Verschuren, Lindeman, Jongmans, & Ketelaar, 2013; Harding et al., 2009; Imms, Reilly, Carlin, & Dodd, 2008; King et al., 2009; Law et al., 2006). Therefore, individuals with disabilities are more inclined to engage in participation that is more located in the home, is less diverse, includes activities that are less active, and involves fewer social relationships (Engel-Yeger, Jarus, Anaby, & Law, 2009; Law, 2002; Law et al., 2006; Shikako-Thomas, Majnemer, Law, & Lach, 2015). This is problematic and potentially harmful since participation in recreational and leisure activities is crucial for children and young peoples’ development. Thus, participation in recreational, as well as leisure activities, is considered a primary outcome of interventions (King et al., 2002; Kolehmainen et al., 2011; Shikako-Thomas et al., 2015). However, knowledge is limited about ways to optimise participation that is meaningful and desired by children with physical disabilities (Kang et al., 2014).

Optimal participation is defined as “a subjective, personally determined construct, related to the meaning that is associated with and derived from an individual’s physical, social and self-engagement in activity and life situations” (Palisano et al., 2012, p. 1042). Children with disabilities describe three ways of getting meaning from their life events, and these include: engaging in activities, social interconnection and seeking to understand themselves and their world (King, 2004). Kang and colleagues (2014) argue that it is the quality of participation not quantity that makes participation experiences optimal, and what defines optimal participation is the quality of interaction between the child and their environment. Kang and colleagues (2014) have conceptualised a multidimensional model of
optimal participation for children with physical disabilities (see Figure 1). Optimal participation in leisure and recreational activities involves interaction between a number of dimensions and determinants of participation (Kang et al., 2014). The dimensions of participation are physical, social and self-engagement; and the determinants include attributes of the child, family and environment (Kang et al., 2014). The model proposes that optimal participation experiences can result in long-term benefits including a healthier lifestyle, emotional and psychosocial well-being, and ultimately a better quality of life.

Figure 1 Conceptual model of optimal participation of children with physical disabilities (Kang et al., 2014)
Dimensions of participation.

Physical engagement is the act of *doing* the activity (Kang et al., 2014). Doing is central to participation and basically means taking part in an activity for as long as the child wishes (Kang et al., 2014). It is evident that children and young people with disabilities wish to actively engage in their chosen activity rather than just being physically present (Eriksson & Granlund, 2004).

Social engagement refers to a child’s engagement in interpersonal interactions that take place while they are participating in the activity and when they are feeling included or get a sense of belonging (Kang et al., 2014). Sense of belonging and social interactions are key ingredients of optimal participation for children and young people with physical disabilities (Hammel et al., 2008; Heah et al., 2007; King, Cathers, Polgar, MacKinnon, & Havens, 2000). It is believed that a sense of belonging is one way of getting meaning through participation experiences (King, 2004) and provides motivation for participation in a desired activity (Allender, Cowburn, & Foster, 2006; Specht, King, Brown, & Foris, 2002; Yuen, Pedlar, & Mannell, 2005).

Self-engagement refers to a child’s self-determination, self-understanding and enjoyment resulting from participation in a chosen activity (Kang et al., 2014). A sense of enjoyment is not only a positive experience but also a motivator for selecting and continuing participation in a particular activity (Allender et al., 2006; Barletta & Loy, 2006; Hohepa, Schofield, & Kolt, 2006; Specht et al., 2002). It is believed that an individual can achieve self-determination by having choice and control over activities of interest (Kang et al., 2014). It is evident that young people with disabilities want to choose the specific activities to participate in and have control over when and how they would like to participate (Passmore, 2003). Self-understanding is when an individual learns new things about themselves and develops a sense of self-concept (Kang et al., 2014).
Determinants of Participation.

Despite the known benefits of participation, there are a number of determinants that can impact a child’s participation (Kang et al., 2014). A number of authors have contributed to knowledge about factors, also known as determinants, for participation in Kang and colleagues’ (2014) model. The commonly agreed upon determinants include: child factors, family factors, and environmental factors (Anaby et al., 2013; Anaby et al., 2014; Kang et al., 2014; King et al., 2003; Law, 2002; Law, Petrenchik, King, & Hurley, 2007; Welsh, Jarvis, Hammal, & Colver, 2006). These have been synthesised and are displayed in Table 1.

Table 1
Determinants Influencing Participation for Children with Disabilities

<table>
<thead>
<tr>
<th>Determinants Influencing Participation</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>Age, gender</td>
</tr>
<tr>
<td>(Bendixen et al., 2012; Kang et al., 2014; King et al., 2003; King et al., 2009; Law, 2002; Mc Manus, Corcoran, &amp; Perry, 2008; Rimmer, Riley, Wang, Rauworth, &amp; Jurkowski, 2004)</td>
<td>Functional abilities</td>
</tr>
<tr>
<td></td>
<td>Skills</td>
</tr>
<tr>
<td></td>
<td>Interests</td>
</tr>
<tr>
<td></td>
<td>Lack of choice</td>
</tr>
<tr>
<td></td>
<td>Lack of motivation</td>
</tr>
<tr>
<td>Family</td>
<td>Family culture</td>
</tr>
<tr>
<td>(Kang et al., 2014; King et al., 2003; Law, 2002; Law et al., 2006)</td>
<td>Education</td>
</tr>
<tr>
<td></td>
<td>Poverty</td>
</tr>
<tr>
<td>Environment</td>
<td>Lack of community programs</td>
</tr>
<tr>
<td>(Almqvist &amp; Granlund, 2005; Anaby et al., 2013; Anaby et al., 2014; Dunn, 1990; Hammal, Jarvis, &amp;</td>
<td>Cost of programs</td>
</tr>
<tr>
<td></td>
<td>Lack of information</td>
</tr>
</tbody>
</table>
A number of personal attributes such as gender, age, individual interest, skills, and a sense of control and competence all influence and determine participation and enjoyment (Kang et al., 2014; Law, 2002). Further, interpersonal skills, communication, problem solving and decision-making skills are also necessary for participation (Law, 2002). Issues such as pain, severely impaired mobility, communication, and intellectual abilities can also result in lower participation (Fauconnier, 2009). Motivation is another key factor that impacts participation.

Motivation is concerned with factors that drive people to act, think, and develop (Deci & Ryan, 2008a). As a result, motivation research is focused on the processes and conditions that facilitate performance, persistence, healthy development and vitality in everyday life (Deci & Ryan, 2008a). Most theories of motivation have considered the concept as unitary and have assumed that when individuals are more motivated, they will accomplish greater achievement and success (Baumeister & Vohs, 2007). One theory of motivation, self-determination theory (Deci & Ryan, 2000; Ryan & Deci, 2000), has challenged this idea. Self-determination theory highlights people’s psychological needs: autonomy, competence, and relatedness as fundamental motivational assets that, when supported, result in optimal participation.
functioning and ultimately psychological wellbeing (Deci et al., 2001; Seligman & Csikszentmihalyi, 2000). There are different types of motivations: autonomous and controlled motivation; and it is argued that it is the type of motivation, rather than the amount, that results in positive outcomes (Deci & Ryan, 2000; Ryan & Deci, 2000). Autonomous motivation is when an individual behaves with a full sense of desire and choice, whereas controlled motivation is when the individual behaves with the experience of pressure from external forces with the aim to achieve a specific outcome (Deci & Ryan, 2008a). Therefore, it is argued that autonomous motivation and controlled motivation lead to different outcomes, with autonomous motivation resulting in greater psychological health and better performance in participation (Deci & Ryan, 2008b). Self-determination theory assumes that people are naturally active and self-motivated, curious, interested and willing to succeed because success is satisfying and rewarding (Deci & Ryan, 2008a). However, every individual’s environment can either support or prevent self-determination (Deci & Ryan, 2008a).

**Family.**

Young people with disabilities’ are reported to have increased social and community participation when they receive support from their family and friends (Yeung & Towers, 2014). Factors within families that impact participation include: socioeconomic status, family participation, and activity preferences and parental overprotection.

**Socioeconomic status.**

A family’s socioeconomic status has a direct impact on children and young peoples’ participation (Almasri et al., 2011; Carlson, Bitterman, & Daley, 2010; King et al., 2006; Law et al., 2006). Families of children with disabilities have an overall lower income than families whose children are not disabled (Mihaylov, Jarvis, Colver, & Beresford, 2004). This could potentially be due to the parents’ caring responsibility for a child with a disability.
Furthermore, Law et al. (2006) highlighted that participation of children with disabilities is less diverse in families reporting lower income, single parent status, and lower respondent parent education. In contrast, families with a higher socioeconomic status have a lesser need for financial and family support and are better able to access services and the community (Almasri, O’Neil, & Palisano, 2014).

*Family participation and activity preferences.*

Not surprisingly, family preferences impact the child and young persons’ participation. For example, if parents within a family unit are interested in active recreational activities, then the children will typically participate in these activities (Law, 2002). In addition, parental support (King et al., 2007; Law et al., 1999; Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006; McManus et al., 2006) and parental involvement in arranging play (Heah et al., 2007) all facilitate and enhance participation for children with physical disabilities.

*Parental overprotection.*

In a study by Heah and colleagues (2007), parents of children with physical disabilities recognised that overprotecting their children may be limiting their child’s participation. Parental overprotection is defined as a level of protective parenting *behaviour*, which is believed to be excessive given their child’s developmental stage (Thomasgard, Metz, Edelbrock, & Shonkoff, 1995). This parenting style has been increasingly recognised in the social science literature and has been interchangeably used with other terms such as ‘helicopter parenting’ (LeMoyne & Buchanan, 2011), ‘parenting out of control’ (Nelson, 2010), overinvolved parenting (Givertz & Segrin, 2014), or ‘overparenting’ (Segrin, Woszidlo, Givertz, Bauer, & Taylor Murphy, 2012). According to Segrin et al. (2013) overparenting also involves excessive parenting involvement, anticipatory problem solving by the parent and risk aversion in a bid to keep the child out of harm’s way.
• **Cause of overprotection**

Undoubtedly, raising a child can be difficult for parents, and parents of children and young people with disabilities have the added physical and psychological demands of trying to adjust emotionally (Sanders, 2006). The unpredictable nature of many chronic and disabling conditions such as neuromuscular disease can have a profound impact on adjustment outcomes among parents (Stewart & Mishel, 2000). Research on parental overprotection highlights anxiety as a potential cause for over protectiveness (Rapee, 2009; Thomasgard, 1998). Thomasgard (1998) and later Segrin et al. (2013) found that anxious parents viewed their children as vulnerable and therefore, resorted to overprotection as a possible solution to their concerns.

Children and young people are dependent on adults to access everyday activities. However, parents’ choice of activity for their child may be influenced by their own perception of risk (Niehues, Bundy, Broom, & Tranter, 2013). Since adults are entrusted to be the caregivers of children, their primary concern will be the safety of the child (Niehues et al., 2013). Risk prompts fear, which is a strong negative emotion that narrows human action to protection that is to fight, flight or freeze (Fredrickson, 2001). A qualitative study by Niehues and colleagues (2013) explored parents’ perception of risk and the influences these perceptions had on children’s access to age-appropriate risk taking activities. Results in this study indicated that those parents who had lived a fairly risk-free life were cautious of risk taking and viewed their children as vulnerable and in need of protection. To contain their worries, they either did everything with their children or completely avoided activities that made them feel uncomfortable. Rather than viewing risk as a way of promoting resilience, these parents approached risk fearfully and unintentionally modeled worry and anxiety for their children. In contrast, parents who had experienced significant risk in their lives deliberately supported their children’s engagement in activities that felt risky. These parents
embraced risk as a way for their children to engage in activities to broaden their life experiences and at the same time build skills, show compassion and generate positive, instead of negative, emotions. By viewing risk as an opportunity or challenge, these parents provided their children with autonomy support, i.e., structure, guidance and connectedness (Grolnick, 2009; Grolnick & Seal, 2008) to allow them to be happy in the present and to gain life skills needed to flourish in the future (Niehues et al., 2013).

According to Grolnick and Seal (2008) it takes both time and effort for parents to offer autonomy support to their children; and when parents feel pressured, their reaction is to increase control. It is often easier for parents to just say “no” to activities that, in their view, are risky. If parents feel uncomfortable with risk taking, then the children and the family miss out on the benefits of age-appropriate risk taking (Grolnick & Seal, 2008). This may include: the opportunity to experience happiness and other positive emotions, a sense of achievement, and developing resilience (Grolnick & Seal, 2008). Within the context of the family, overprotection is often considered a barrier to social experiences; however, parental overprotection can be a response to an unsupportive social system (Baker & Donelly, 2001).

- **Impact of Overprotection**

Parental overprotection has been shown to have negative consequences on children and young peoples’ psychological wellbeing (Holmbeck et al., 2002; Sanders, 2006). In children and young people, parental overprotection has been associated with anxiety, withdrawal, depression and low self-esteem and confidence (Bayer, Sanson, & Hemphill, 2006; Gar & Hudson, 2008; Holmbeck et al., 2002; Kim, Wang, Orozco-Lapray, Shen, & Murtuza, 2013; Sanders, 2006; Segrin et al., 2013). Parents who overprotect a child with a disability have been shown to continue this behaviour as the child transitions into adolescence and young adulthood (Sanders, 2006). For example, parents may not allow the young person to enter the workforce because of feared risks (Sanders, 2006). This
overprotection in young people can result in dependent personality traits and neuroticism (Liss & Schiffrin, 2014; Montgomery, 2010), lower self-efficacy (Givertz & Segrin, 2013) and higher entitlement (Segrin et al., 2012). Consequently, young people with disabilities have limited awareness of career options, lack knowledge of the career decision-making process and lack adequate skills for employment (Hitchings et al., 2001).

**Environment.**

The environment (social and physical) can become either a potential support or a barrier to optimal participation (Anaby et al., 2013; Anaby et al., 2014; Law et al., 2006; Welsh et al., 2006). Knowledge about specific environmental barriers and supports serves as a mediator between child/personal factors (income, health condition, functional issues) and participation outcomes (Anaby et al., 2014).

**Social Environment.**

The social environment, including positive social attitudes and availability of social support, is integral to participation (Dreyer, Steffensen, & Pedersen, 2010; Law, 2002; Law et al., 1999; Law et al., 2006; Mc Manus et al., 2008). Children and young people with disabilities are faced with negative social attitudes within society, in general, but also within social institutions such as schools. Therefore there is a need to educate and inform in order to get a better outcome for these individuals.

- **Negative societal attitudes towards disabilities**

Children and young people with physical disabilities are often stigmatised and as a result may not gain full social acceptance (Green, 2007). Stigma and prejudice in society and the community’s perception of disabilities have a negative impact on social experiences and participation (Chan, Lau, Fong, Poon, & Lam, 2005; Green, Davis, Karshmer, Marsh, & Straight, 2005; Hunt, Alwell, Farron-Davis, & Goetz, 1996; Imms, 2008a; King et al., 2006;
Labeling, stereotyping, status loss, separation, and discrimination within society are the five components of stigma (Link & Phelan, 2001). As long as children and young people with disabilities are stigmatised in society, they will continue to experience segregation and minimal opportunity to participate in society.

Children and young people living with a disability are often devalued and discredited by able-bodied people (Barr & Bracchitta, 2015; Louvet, 2007). Individuals without a disability are cautious to form friendships, experience discomfort, and express sadness or pity towards individuals with a disability (Green et al., 2005; Green, 2003, 2007; Weiserbs & Gottlieb, 2000). These feelings can further limit normal social interactions. This can create confusion and social awkwardness which can, in turn, diminish both the quality and quantity of social interactions (Green et al., 2005). On the contrary, others may hold the view that as long as the impairment is minor and temporary, the person is still part of that same community (Green et al., 2005). This is problematic for children and young people who have a permanent or progressive condition (Green et al., 2005).

- **Negative attitudes within the institutions**

Negative attitudes within institutions such as school and the workplace can further segregate and minimise participation for children and young people with disabilities. A Canadian study of seven young people with cerebral palsy and spina bifida and conducted in a school environment, highlighted that the school environment was not inclusive (Doubt & McColl, 2003). Students with disabilities were relegated to a secondary position to non-disabled peers. The environmental barriers that explained this relegation include: negative attitudes, inaccessible activities, and lack of supports (Doubt & McColl, 2003). Interestingly the participants did not view their physical limitations as a barrier to social acceptance and
participation in school activities. In contrast, Harding et al. (2009), who conducted a study with six children (four with physical disabilities and two with developmental disabilities) aged between 8-13 years, reported that children viewed their physical limitations, not the social environment, as a barrier. The participants considered people in the community as helpful (Harding et al., 2009). Both these studies were conducted in Canada. The difference between the two studies include: the environment (school and community), the age difference between the participants and the 3-year time difference between the two studies. This time difference between the two studies may have resulted in the possible shift in attitudes within society and therefore be a contributing factor for the difference in research findings.

- Importance of training and education of care providers

Positive societal attitudes and training of care providers are important predictors for families’ continued access of support services for their children with special needs. A qualitative study conducted with 44 families of children with disabilities highlighted three main themes; 1) importance of establishing trust with service providers, 2) various family and societal barriers and 3) the need to address these barriers (Emira & Thompson, 2011). This study utilised an interpretive paradigm, a qualitative framework, in order to investigate a sensitive issue of societal attitudes. This method was utilised in order to allow the families to express their views and for the researchers to give voice to the participant’s perceptions. The results highlighted the importance of building care providers’ capacity, through training and education, to effectively care for children and young people with disabilities. Further, the importance of care providers building a trusting relationship with families was emphasised.

Physical Environment.

Participation for children and young people with physical disabilities is often limited due to lack of accessibility of buildings (Barf et al., 2009), which includes: building structure
(Mihaylov et al., 2004), access to public transportation and lack of ramps, elevators and parking spaces (Chan et al., 2005). It is evident that for children and young people with disabilities, environmental barriers increase as children move into adolescence and want to participate beyond the home and school (Law et al., 2007). Therefore, an accessible environment where spaces and activities are easy to move in and out of is necessary for these individuals (Woodgate, et al 2012).

Appropriate access to the community plays an important role in enabling participation. Transport is one example of appropriate access to the community. Transportation, including the use of appropriate vehicles and available parking, was identified as a facilitator to participation of children with cerebral palsy (Lawlor et al., 2006). Children and young people with disabilities are at risk of reduced participation without safe, secure, comfortable and specialised transportation (Falkmer, 2001). For example, to access the community, individuals with a physical disability will need to mobilise using a modified vehicle which accommodates their wheelchair or other mobility aids (Unsworth, 2012). In Australia, families are required to purchase and modify their own vehicles, and this places great financial burden on families. Therefore, lack of appropriate transportation is a significant barrier to participation within the community.

Understanding and Measuring Participation

Participation can be explored using quantitative and qualitative research designs. Different quantitative measurement tools are used to understand frequency and variety of activities in everyday participation. At a general population level, time use surveys are being used to understand how people use their time (Dahan-Oliel et al., 2015; King et al., 2007; Law, 2002). In addition to these surveys, a number of measures have been developed to measure children and young peoples’ participation. These measures are presented in Table 2.
Table 2

*Children's Participation Measures*

<table>
<thead>
<tr>
<th>Name</th>
<th>Areas of assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children’s Assessment of Participation and Enjoyment (CAPE) (King et al., 2004)</td>
<td>Participation in leisure and recreation activities</td>
</tr>
<tr>
<td>School Function Assessment (SFA) (Davies, Soon, Young, &amp; Clausen-Yamaki, 2004) and School Outcome Measure (SOM) (McEwen, Arnold, Hansen, &amp; Johnson, 2003)</td>
<td>Participation in the school environment</td>
</tr>
<tr>
<td>Children Helping Out: Responsibilities, Expectations, and Supports (CHORES) (Dunn, 2004)</td>
<td>Participation in household duties</td>
</tr>
<tr>
<td>Assessment of Life Habits (LIFE-H) (Lepage, Noreau, Bernard, &amp; Fougeyrollas, 1998)</td>
<td>Participation in home, school, and community life</td>
</tr>
<tr>
<td>Canadian Occupational Performance Measure (COPM) (Carswell et al., 2004) and Goal Attainment Scaling (GAS) (Becker, Stuifbergen, Rogers, &amp; Timmerman, 2000)</td>
<td>Evaluate goal achievement</td>
</tr>
</tbody>
</table>

The benefits of using these standardised measures are that they provide the capacity to quantify data and their utility in large cohort studies. However, these measures can limit participants’ responses and the richness of data due to predetermined questions and lack of flexibility to explore participants’ responses in depth. For example, these measures do not
provide rich information about activity preferences, meaning or enjoyment (Law, 2002). Therefore, these methods only gather frequency-based information and are not suited to capture the richness of an experience (Polkinghorne, 2005). Whilst it is important to quantify participation for large cohorts, capturing participants’ experiences in detail can further develop knowledge about participation preferences and engagement. Qualitative methods are used to explore how and why a particular phenomenon occurred (Creswell, 2007). Therefore, the researcher aims to gain an in-depth, rich understanding about a particular human experience. For example Heah and colleagues (Heah et al., 2007) adopted qualitative methods in order to study the lived experiences of what participation meant to children with disabilities.

Current Participation Interventions to Improve Participation in Children with Disabilities

Current interventions are aimed at modifying barriers to participation such as the individual’s body function (Imms, 2008b; Novak et al., 2013) and their environment (Darrah et al., 2011). Interventions to improve participation through enhancing body function and structure have shown little or no evidence of effects on participation outcomes (Katalinic et al., 2010). There is some evidence and agreement amongst professionals that participation can be improved by targeting children and young peoples’ activities (Shikako-Thomas, Kolehmainen, Ketelaar, Bult, & Law, 2014). For example, in children with mobility issues, it is evident that powered mobility can improve participation within the family, school and community (Livingstone & Paleg, 2014). There are also a number of interventions which target environmental and/or personal factors, with an aim to improve participation for children and young people with disabilities (Shikako-Thomas et al., 2014). These include interventions targeting the built aspects of the child’s home and school and providing children and their families with information (Henderson et al., 2007).
For participation to occur is it important to minimise barriers and support the child (Law et al., 2006). Current participation literature (Anaby et al., 2014; Bendixen et al., 2012; Bendixen et al., 2014; Bult, Verschuren, Lindeman, Jongmans, & Ketelaar, 2013) focuses on frequency and intensity of activity engagement. However, frequency and intensity of activity participation does not necessarily equate to participation that is considered to be positive to the individual (Chang, Coster, & Helfrich, 2013). Furthermore, the internal or individual elements that lead to optimal participation are not well defined nor are intervention models available to target these specific factors.

**Self-Engagement: Key Ingredient of Participation**

Kang and colleagues (2014) offer a comprehensive conceptual model of optimal participation. The concept of optimal participation is defined as being a collection of determinants and dimensions. The dynamic interaction between the two results in optimal participation (Kang et al., 2014). Notably, self-engagement includes self-determination, self-understanding and enjoyment resulting from participation in a chosen activity. However, Heah and colleagues (2007) used the term ‘successful participation’ to describe engagement in activities with others and performing tasks independently. Furthermore, King and colleagues (2014) reported a number of highly valued aspects of leisure activity settings by young people with severe disabilities. These include engagement with others, enjoying the moment, and control and choice in selection and participation in activity settings (King et al., 2014). Thus, engagement, enjoyment and choice appear to be key ingredient to facilitating participation that is optimal or meaningful to the child or young person (Heah et al., 2007; Kang et al., 2014; King et al., 2014). The children in Heah and colleagues’ (2007) study attached different meanings to successful participation including; having fun, feeling successful, doing things independently, and doing and being with others. Heah et al. (2007) concluded that these themes are consistent with Csikszentmihalyi’s (1975) theory of ‘Flow’,
which is described as a state of deep enjoyment and concentration, where time is often suspended. The theory of flow explains the experience of participation for individuals with and without disabilities. A state of flow occurs when an individual is motivated to participate in an activity, is in control of their environment, feels as though time is at a standstill and their sense of challenge and skill is perfectly matched (Csikszentmihalyi, 1975). Therefore, for an individual to be in a state of flow, there needs to be an element of choice and “just right” challenge. It is understood that, when these elements are present in an activity the individual is highly motivated, and participation becomes more enjoyable resulting in a positive experience or a state of flow (Csikszentmihalyi, 1975). Therefore, Heah and colleagues (2007) offer further insight into how self-engagement can be facilitated and maintained for children and young people with disabilities. This builds on Kang and colleagues’ (2014) model and provides specific guidance about the experience and process of optimal participation.

Choice

Choice making is part of everyday life and key to achieving independence and autonomy and ultimately self-determination. The ability to delicately match challenge and skill rests with the individual’s ability to make choices. Choice is defined as an opportunity to make an independent selection free from coercion with no consequences apart from the consequence resulting from that selection (Brown & Brown, 2009). Brown and colleagues (1997) conceptualised choice as a process that involved two broad steps: 1) having opportunities available and 2) making decisions from the available opportunities. Wehmeyer (2007) expanded the concept of decision making that he called ‘choice making’, which involves identifying a preference and making a selection from options available.

Providing individuals with the opportunity to make choices will promote greater engagement and motivation (Mithaug, 2005). This is attributed to the fact that the individual
has the choice to select activities that matches their interests and skills (Mithaug, 2005). A number of research studies have examined the effect of choice on participation (Rabiee & Glendinning, 2010; Woodgate, Edwards, & Ripat, 2012). Limited participation of children and young people with disabilities has been attributed to a lack of choice (King et al., 2009). Parents of children and young people with disabilities are often the ones making choices on behalf of their children for various reasons. These include: lack of available programs, physical barriers, their desire to provide their children with particular experiences and their own needs for respite from their caregiving role (King et al., 2009). Children and young people with disabilities need to engage in age appropriate choice making opportunities. For example, a young adult with disabilities can make choices about where they would like to live, with whom they want to associate, how they spend their money, what they want to eat and what clothing they want to wear (Honoré, 2008). Woodgate and Colleagues (2012) argue that for participation to be meaningful to children, elements of choice, safety, acceptance, accessibility and accommodation need to be present. Having choice contributes to an individuals’ autonomous or intrinsic motivation to participate in activity (King et al., 2009).

Choice and choice making are considered central elements of self-determination (Wehmeyer, 2007). Providing choice to individuals with disabilities will allow them to have some autonomy and control over their lives and the decisions that impact them (Mithaug, 2005). Therefore, choice represents the key element and the starting point of self-determination (Agran 2010). Individuals who have achieved self-determination are able to continually seek out greater challenges, are intrinsically motivated, and are able to achieve their full potential (Seligman & Csikszentmihalyi, 2000). Furthermore, self-determined individuals make choices, act on those choices they make and experience the results from those choices (Martin, Woods, Sylvester, & Gardner, 2005).
Overprotection can be noticed at both individual (i.e. parental) and societal levels (Sanders, 2006). Overprotection from either level can be detrimental to the lives of children and young people living with a disability, as it can limit life experiences. Often parents of children with disabilities and service providers restrict the child’s choices in order to minimise perceived risks (McLaughlin, 2008). Parents find it difficult to maintain a balance between risk and protection, and often protecting their child is more important (Davis & Wehmeyer, 1991). As a consequence of overprotection by parents, these children are given the least chance to develop their identity, and experience choice making and control (Arellano & Peralta, 2013).

Choice and choice making are well represented in intellectual disability and mental health literature (Agran, Krupp, & Storey, 2010; Brown & Brown, 2009; Duvdevany, Ben-Zur, & Ambar, 2002; Finlay, Walton, & Antaki, 2008; Harris, 2003; Laugharne & Priebe, 2006; Rabiee & Glendinning, 2010; Wehmeyer & Bolding, 2001). Conversely, research exploring choice for people with physical disabilities including neuromuscular conditions is exiguous. This could potentially be due to the assumption that it is cognitive impairment rather than physical disability that impacts on choice and therefore, these individuals are able to make independent choices.

Historically children and young people with disabilities, in particular those with intellectual or developmental disabilities, have been denied the right to express their preferences, make their own choices based on those preferences, and act on those choices (Agran, Hong, & Blankenship, 2007; Brown & Brown, 2009; Honoré, 2008; Mithaug, 1998; Neely-Barnes, Marcenko, Weber, & Charles Lakin, 2008; Wehmeyer, 1998; Wehmeyer, Agran, & Hughes, 2000). It is evident that the more severe the child’s disability, the fewer choice opportunities are provided to them (Lawlor & Mattingly, 1998; Welsh et al., 2006; Whiteneck et al., 2004). Our understanding of the degree of choice opportunities that are
provided to children and young people with disabilities, and the type of choices they make is often obtained from proxy reporting by parents or service providers rather than the individuals themselves (Larson & Verma, 1999). Believing that a loved one is not making the correct choice can be an emotional challenge (Brown, Cobigo, & Taylor, 2015) and can lead to parents, caregivers and service providers wanting to protect the child or young person from making an incorrect choice (Finlay et al., 2008; Harris, 2003) Furthermore, at times, choices that are made by others may be in the interest of time, money and protectiveness, not the preferences of the child or young person (Brown & Brown, 2009; Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1989).

**Challenge**

Flow is facilitated by a match between challenge of the activity and the young person’s skill. When this equilibrium is achieved, the term ‘flow’ is used to describe their experience (Hektner & Csikszentmihalyi, 1996). A perfect match between the challenge of the activity and the individual’s skills results in participation that is enjoyable, confidence boosting and skill building (Csikszentmihalyi & LeFevre, 1989). Furthermore, when the activity is novel, sufficiently challenging, goal oriented and bound by rules, optimal experience is sustained (Csikszentmihalyi, 1990; Deci, 1992). In order to maintain the enjoyment of flow, young people need to continue to participate in new challenges to match their increasing skills, since an individual’s level of skills increases with practice and age (Hektner & Csikszentmihalyi, 1996). Optimally challenging activities will require a person to stretch their existing capacities however, not to the point that it becomes impossible (Hektner & Csikszentmihalyi, 1996).

Lowered expectations occur when less is expected from a child or young person, not based on fact or their real capability. An example is when a child does not pass a test but is given a pass out of sympathy (Sanders, 2006). These lowered expectations can continue into
secondary school; and when these young persons enter further education, they struggle due to lack of expectation to succeed in school (Yuen & Shaughnessy, 2001). Therefore, rewarding a child or young person for minor accomplishments may be both disrespectful and counterproductive if they are capable of achieving greater things (Sanders, 2006). According to Sanders (2006), one of the consequences of lowered expectations is that the child or young person with the disability may start to believe that the disability is the cause of their incompetence. As a result, this can lead to a decrease in participation.

The negative effects of lowered expectations have long lasting consequences on children and young people (Sanders, 2006). The internalization of lowered expectation can cause the child or young person with the disability to believe that they are incapable; and when they are not expected to do more, they do not. Every aspect of life including vocational prospects, educational opportunities and recreational activities are affected (Sanders, 2006). As an example, some services and programs designed to encourage independence and participation in the community can restrict independence and may focus on ‘disability’ instead of ‘ability’ (Darrah, Magill-Evans, & Galambos, 2010).

Children and young people with disabilities are at risk of being unable to achieve the “just right challenge” due to both societal and personal barriers. The societal barriers such as attitudes and environment can preclude the participation of children and young people with a disability (Dreyer et al., 2010; Law, 2002; Law et al., 1999; Law et al., 2006). The individual barriers such as socioeconomic status, health status and motivation can also prevent a child or young person from participating in day-to-day life (King et al., 2006; Law, 2002). In a study which investigated agreement between boys and their parents when reporting on health related quality of life, boys with DMD reported that they felt under-challenged when participating in activities (Bray, Bundy, et al., 2010). One possible cause for this might be that as a society, we place low expectations on these individuals.
Summary

Participation in society is a universal goal and vision for many people. Through participation, we gain and develop skills, build relationships and networks, set goals and gain purpose in life. As a result, participation has various benefits and implications on quality of life and is crucial for human development. There is an abundance of literature discussing participation and its importance, measurement frequency of participation as well as interventions focusing on modifying body functions and the individual’s environment to increase participation. However, these interventions fail to focus on ways to promote opportunities for children and young people with disabilities to experience choice and challenge. It is evident that in order to achieve a higher degree or intensity of participation, choice and challenge need to be present. This re-framing and expansion of engagement in activity can hold the key to designing interventions to enhance participation for children and young people with disabilities. In addition to these factors, appropriate environmental supports need to be available, including encouraging and supporting parents as well as training support people to maximise potential in children and young people with a disability. Despite current literature identifying key ingredients in achieving optimal participation in choice and challenge, there is a gap in literature focusing on interventions aimed at achieving optimal participation for children and young people with disabilities and is almost non-existent in the neuromuscular disease population.
CHAPTER THREE - METHODOLOGY AND METHODS

The aim of this study was to gain an in-depth understanding of the personal experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award as well as the experiences of their parents. In this chapter I will detail the methodology and consequent methods that I chose and used to achieve the study aims. In brief, I used a qualitative research methodology specifically, thematic analysis and employed some of the systematic methods of a constructivist grounded theory approach to guide the process of data collection and analysis.

Methodology

Qualitative Research Methodology

Qualitative research is an umbrella term that refers to research activities that enable the researcher to enter the world of the research participant in order to study and attempt to see the world according to that participant (Denzin & Lincoln, 2011). In qualitative research, the researcher relies on textual data rather than numerical data by analysing the data in its textual form instead of converting the data into numbers (Carter & Little, 2007). The aim is not to test a previously developed hypothesis but rather, to understand and make sense of human experience (Carter & Little, 2007). In this study, my aim was to gain an in-depth, rich understanding about a particular human experience. In order to capture the richness of this experience, I chose to employ thematic analysis (Braun & Clarke, 2006) as the primary qualitative research methodology in conjunction with some of the guiding principles or methods of a constructivist grounded theory approach. It is important to emphasise that the aim of my research study was not to develop theory and therefore this is not a grounded theory study. Rather, I chose to employ some of the systematic and rigorous process and methods of the constructivist grounded theory methodology to enhance the rigour of my
study. In the following paragraphs I will provide a brief introduction to thematic analysis and then constructive grounded theory methodology and methods employed.

**Thematic Analysis**

Thematic analysis is a commonly used qualitative analytic method, however it is often poorly defined and infrequently acknowledged as the methodology used by authors (Roulston, 2001). Thematic analysis has been defined as a method of identifying, analysing and reporting patterns or themes within data (Braun & Clarke, 2006). According to Taylor and Ussher (2001), the researcher plays an active role in identifying patterns or themes within the data, selecting the themes that are of interest to the question or questions being asked, and reporting them to the reader. There is debate within the literature about whether thematic analysis is merely a research tool or rather, a standalone methodology. Some researchers believe that thematic analysis is a tool that is used across different methodologies including grounded theory and therefore not a specific approach in its own right (Boyatzis, 1998; Denzin & Lincoln, 2008). Others claim that thematic analysis should be regarded as a methodology in its own right (Braun & Clarke, 2006).

**Principles of Constructivist Grounded Theory**

Grounded theory is a specific qualitative methodology developed by sociologists, Glaser and Strauss, in the 1960s (Glaser & Strauss, 1967). It is a methodology that can help researchers understand or explain particular phenomena or experience (Creswell, 2007). In grounded theory, the researcher adopts an inductive approach where the data collected and analysed will give insight into a particular phenomenon and build on current understanding (Strauss & Corbin, 1998). The aim of the research is then to develop an understanding of the meanings participants attach to the phenomenon or experience being investigated (Charmaz, 2014). Grounded theory methodology has evolved with various adaptations being made to the
traditional form developed by Glaser and Strauss (1967). For this study, I chose the constructivist framework of grounded theory developed by Kathy Charmaz (2014).

Constructivist grounded theory is commonly used in health research to develop understandings of the different ways people interpret and understand their experiences in their world (Charmaz, 2014). It is based on the epistemological understanding that knowledge is constructed through interactions between the researcher and the research participants (Charmaz, 2014). Charmaz claims that knowledge of a particular phenomenon does not just emerge from the data independent of the researcher but suggests that theories are constructed from the interaction between the researcher, the participant and the overall research process.

Constructivist grounded theory methodology has various strengths. Firstly, the method provides rigorous, systematic and specific procedures, which help the development of categories that start with, and remain close to, the qualitative data being collected. Secondly, this methodology is an interpretive approach where the researcher seeks to explore real-life situations and therefore requires or acknowledges a high degree of interaction between the researcher and the individual. The constructivist grounded theory approach (Charmaz, 2014) provided me with a compatible framework for investigating the experiences I examined in my research study: the experiences of young people with neuromuscular disease and their parents participating in the Duke of Edinburgh’s Award.

In her book ‘Constructing Grounded Theory’, Charmaz (2014) provides a set of practices to guide the research methods to employ throughout the processes of data collection, analysis and construction of categories. These include: coding, constant comparative analysis, concurrent data collection and analysis, and memo-writing. Charmaz recommends that researchers use these methods in a flexible manner to suit the particular
research study. These recommended methods will be briefly outlined below within the relevant sections in which I describe how I applied them within this study.

**Methods**

Methods are thought of as techniques and tools or research actions (Carter & Little, 2007; Dew, 2007). Research methods are the hands-on activities that include sampling, data collection, data management, data analysis and reporting (Carter & Little, 2007). In qualitative research, it is crucial that there is a match between the methodology selected and the methods used (Richard & Morse, 2012). As stated above, the methods used in this study were guided by the systematic yet flexible processes recommended by Charmaz (2014). While I am reporting them here in a linear order for ease of reading, consistent with grounded theory principles, this was in fact an iterative, non-linear process of data collection and data coding (Charmaz, 2014).

**Ethical Approval**

Prior to the commencement of this study, I obtained ethical approval from the University of Sydney Human Research Ethics Committee. The letter of approval is provided in Appendix (No. 1).

**Setting of the Study**

This study was conducted in the Australian state of New South Wales (NSW), a state in the east of Australia. This study was conducted across both rural and metropolitan areas of NSW.

**Sampling**

In this study, I used purposive, non-probability, homogeneous sampling (Grbich, 1999) to recruit information rich participants. Purposive sampling is commonly used in qualitative research and involves recruiting participants for the study based on their knowledge and experience of the phenomenon being investigated (Merriam, 2002). According to Patton
(1990), “information rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposive sampling” (p. 169). In this study, 17 young people living with a neuromuscular condition who had been enrolled in the Duke of Edinburgh’s Award and had completed, or were near completion of, at least their Bronze level as well as their parents were invited to participate in individual interviews. Out of the possible 17 young people, eight young people and their parents, mainly mothers and one grandmother (n=8), consented to participate in the study and were interviewed about their experience of the Award. Thus, almost half of all potential participants chose to be involved in the study.

**Participant Eligibility Criteria**

In this study the inclusion criteria for the young person and parent participants were:

- Young person must have been enrolled in the Duke of Edinburgh’s Award through the Muscular Dystrophy Association of New South Wales (MDNSW) and had made considerable progress in the program (completed or were near completion of at least their Bronze level)

- Young person and their parents must be able to communicate in English

All volunteering participants did meet these criteria.

**Participant Recruitment**

The MDNSW was involved in the recruitment process by making initial contact with potential participants to ensure there was no perceived coercion by me as the researcher. I did not have access to potential participant details. These details were kept with the Duke of Edinburgh’s Award coordinators at MDNSW. I developed mailing packs containing a letter of invitation (Appendix No. 2), child participant information sheet (Appendix No. 3) and adult participant information sheet (Appendix No. 4), the child consent form (Appendix No. 5) and adult consent forms (Appendix No. 6), and an opt-in slip (Appendix No. 7). I then
sent these mailing packs to MDNSW who then sent out mailing packs to the 17 young people and their families. Separate information sheets and consent forms were designed for the young person and their parents. Interested participants were asked to contact me directly. The information sheets informed all potential participants that they were under no obligation to take part in the research and that their decision would not in any way affect their relationship with myself, MDNSW or the Duke of Edinburgh Award Australia.

**Participants**

In total, 16 people participated in the study. Eight Dukies (five females and three males aged between 16-24) and their parents (seven mothers and one grandmother) made contact with me to volunteer to participate in the research study. Demographic details of the Dukies are presented in Table 3. Demographic details of parents who participated in the research study are presented in Table 4. Further demographic information regarding the research participants has not been provided in order to protect the anonymity of participants given the small and connected community they come from, i.e., young people living with a neuromuscular disease in NSW.
<table>
<thead>
<tr>
<th>Characteristic</th>
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<td>Spinal Muscular Atrophy II</td>
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<tr>
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<td>Fulltime wheelchair user</td>
<td>7</td>
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<td>Walking</td>
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<td>Duke of Edinburgh’s Award level</td>
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<tr>
<td>Non completion of Bronze Award*</td>
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</tr>
<tr>
<td>Completed Bronze Award</td>
<td>2</td>
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<tr>
<td>Enrolled in Silver Award</td>
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<tr>
<td>Completed Silver Award</td>
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<tr>
<td>Enrolled in Gold Award</td>
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*Participant unable to complete due to his age (reaching 26 years)
Table 4

Demographic Characteristics of Parents

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<td>Mother</td>
<td>7</td>
</tr>
<tr>
<td>Grandmother</td>
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Data Collection

Ethical Issues and Informed Consent

To ensure confidentiality and protect participant information, I compiled a master list at the time of the initial consent and collection of demographic data. I then allocated pseudonyms for the young person and parent. All materials relating to individual respondents were identified only using pseudonyms. The letter “D” follows these pseudonyms when they are Dukies, while the letter “P” follows when they are parents. The master list was stored in a locked filing cabinet which was only accessible by the research team. I stored all interview records, written and audio taped, in a locked filing cabinet. I also ensured that transcripts and recordings were stored in password protected computer files.

I explained the nature and purpose of the study to all participants both in writing and verbally before I sought consent. All participants completed written consent forms prior to interviews taking place, and I have securely retained these consent forms.

I ensured that contingency plans were in place for the very unlikely event of possible emotional distress for participants as a result of the interview. If this occurred during the interview, I would give the participant the choice to terminate the interview. I would then provide the participant with contact details for the MDNSW psychologist to contact for
counseling support. I had made prior arrangements with MDNSW psychologist to provide support to participants should any concerns arise. Fortunately, no such concerns arose.

**Interviews**

Prior to the study commencing, I attended multiple meetings with the organisers of the Award at MDNSW and executive staff at the Duke of Edinburgh’s Award Australia in order to learn more about the Award. Following this, I met with two supervisors and developed separate semi-structured interview guides, one for the young person (Appendix No. 8) and the other for the parents (Appendix No. 9).

During the semi-structured interviews, I used the interview guides as a tool to ensure a degree of focus while facilitating in-depth discussion in regards to different topics. As I was the person conducting the interviews, I was required to make a conscious effort not to impose my own viewpoints, to constantly ask open-ended questions, and repeatedly use probing questions to elicit rich and in-depth responses from participants. I also encouraged participants to discuss issues and experiences that were of importance to them and which I had not raised. As the interviewing process continued, I amended the interview guide to include exploration of insights which I gained from earlier participants (DiCicco-Bloom & Crabtree, 2006).

Questions for the young person focused on i) their overall experience of the program ii) life prior to the program and, iii) life post the Duke of Edinburgh’s Award. Questions for the parents focused on i) parent’s personal experience of their child participating in the Award, ii) their views on their child’s participation in the Award, iii) whether they had noticed any change in their child following their participation in the Award and, iv) the impact of the Award on the family unit.
I conducted individual, face-to-face, semi-structured interviews with each young person, and separately, with their parent. I conducted these semi-structured interviews with the participants at their preferred location. The majority of the interviews (14 out of 16 interviews) were conducted at the participant’s family home with an exception of two, where the young person was interviewed at a disability organisation and their mother interviewed at her workplace. Interview times ranged from 45 minutes to 90 minutes and, on average, one hour long. I audio-recorded all interviews and then transcribed verbatim audio taped data from each interview.

As recommended by Charmaz (2014), I engaged in a process of memo-writing immediately following each interview. I reflected on the interview and documented what I had heard, any unexpected events that had occurred during the interview and whether anything needed to be changed before the next individual interview.

Data Analysis

Coding

Following the first four interviews with two Dukies and their parents, I met with my research supervisors; and a decision was made to make some minor changes to the interview guides to capture areas that were brought to my attention by the first four interviews. I used NVivo 8 software for data management and initial stages of coding.

In this study, I conducted my coding according to the processes of initial coding, focused coding, and development of broader categories as recommended by Charmaz (2014). This data analysis process is presented in Figure 2. In studies, using Charmaz’s principles of constructivist grounded theory approach, data analysis begins with initial coding of data records and then coding becoming more focused in the later stages of the analysis in order to generate categories (Charmaz, 2014). According to Charmaz, throughout this process, data
must be constantly compared to data, data with codes, codes with other codes, codes with categories and categories with other categories.

**Initial coding.**

Initial coding according to Charmaz (2014) involves labelling, sorting and defining the data. It is important that the initial codes reflect exactly the perspectives and meanings specific to the research participants so that the categories are a true reflection of the participant's experiences (Charmaz, 2014). During the initial coding stage, it is important to stay ‘close’ to the data and to keep coding simple and precise while remaining open to what the data suggests (Charmaz, 2014). Initial coding can occur word-by-word, line-by-line, section-by-section and incident-to-incident or using a combination of the four methods (Charmaz, 2014).
Figure 2 Data analysis process
One of my associate research supervisors (NH) and I began the process of initial coding by independently analysing the same first two transcripts to create initial codes. We then met to discuss our codes and find consensus to establish consistency with our coding and to enhance rigour. The initial coding process involved my looking at the data closely, line-by-line or section-by-section and coding each of these. For example the two quotes, below, from two different Dukies were grouped together under the initial code ‘*I now know I can do pretty much everything... like everyone else*’ (Self-belief).

- “*I feel more ready to face things and I feel like now that I have done the [Duke of Edinburgh’s Award], I can do so much more than what I said I couldn’t do... It [Duke of Edinburgh’s Award] has encouraged me to have a go at different things that I might not have been willing to have a go at previously*” Kristy (D).
- “…*The Duke makes me feel like I am not limited with my disability. There are a lot of things that I can’t do but the Duke makes me feel like there is nothing I can’t do. I can do pretty much everything like everyone else and succeed like everyone else*” Jennifer (D)

As I went through the data, I grouped the data that expressed similar ideas. As I coded more and more data, the number of initial codes increased and new data was either coded to existing codes or new codes.

**Focused coding.**

After all data had been coded, I ended up with a large number of initial codes. In collaboration with my supervisors, I then commenced a process of focused coding (Charmaz, 2014) in which I compared initial codes to one another, examining the relationships between them in order to identify and group those codes which were related or expressed the same
idea or broader concept. For example, the following initial codes were grouped together as a focussed code called ‘What Dukies got from engaging in the Award’

- ‘It helped me communicate with others’ (Social confidence)
- ‘I now know I can do pretty much everything... like everyone else’ (Self-belief)
- ‘Thinking bigger and beyond the box... thinking wider and broader’ (New outlook/perspective on life)
- ‘Got me more independent, doing stuff for myself’ (Learning independence)
- ‘I got to go out into the community’ (Increased community participation)
- ‘I met someone else with the same disability that understands what it’s like’
  (connection and attitude towards disability)
- ‘I have achieved goals I set myself’ (Sense of accomplishment)
- ‘Improvement in Dukie’s health’

According to Charmaz (2014), focus coding involves using the most frequent, significant or related codes in order to sort and combine large amounts of data. These focus codes form the basis for broader categories (Charmaz, 2014).

**Development of categories.**

As the coding process continued and focused codes were reviewed and compared, categories were generated. For example the focused codes ‘Dukies initial thoughts and feelings about the Duke of Edinburgh’s Award’ and ‘What Dukies got from engaging in the Award’ were developed into a broader category titled ‘A life worth smiling about: the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award’.

Additionally the focused codes ‘parent’s initial feelings about the award’ and ‘what the parents got from their child’s participation in the Duke of Edinburgh’s Award’ were generated into a
broader category named ‘letting go: the experiences of parents of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award’. Finally the focused codes ‘choice’, ‘just-right challenge’, ‘access to resources and support from MDNSW’ were categorised under ‘essential ingredients of the Award’. Therefore, the final categories generated by the analysis include: i) Initial motivations: “Why we decided to do it”, ii) A life worth smiling about: the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award iii) Letting go: The experiences of parents of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award, and iv) Components that enhanced participation. These categories will be discussed in detail in the Results.

**Data Saturation**

In this research study, data collection and analysis continued until we had reached data saturation. The concept of data saturation was first introduced by Glaser and Strauss (Glaser & Strauss, 1967), and it refers to the point in data collection when extra interview data is not adding further insight or depth to the categories developed. Through the analysis of the data gathered in consultation with my research supervisors, we decided that the data collected was adequate for data saturation. This was due to the group interviewed being fertile exemplars of the very specific experience under investigation. If required, another round of participants would have been recruited since by this point in time, further young people had progressed through the Award and would thus have met the inclusion criteria set for the study.

**Summary**

Overall, this study aims to gain a rich, in-depth understanding of the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award. In order to achieve the goals of this research I used qualitative thematic analysis research
methodology and employed some grounded theory methods to guide the research process. This process started with in-depth face-to-face semi-structured interviews with eight young people living with a neuromuscular disease who were participating in the Duke of Edinburgh’s Award. Separate interviews were conducted with their parents, eight in total. Categories were ultimately identified from this qualitative data and in the following chapter, these categories will be discussed in detail.
CHAPTER FOUR - RESULTS

This chapter presents findings from analysis of interviews conducted with Dukies and separately, their parents. Thematic analysis of data from Dukie and parent interviews, using principles of grounded theory, resulted in four broad categories:

i) Initial motivations: “Why we decided to do it”

ii) A life worth smiling about: the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award

iii) Letting go: The experiences of parents of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award, and

iv) Components that enhanced participation

The above categories are detailed below and illustrated using participants’ verbatim quotes. Where possible, categories have been labeled using the direct words of participants in order to truly capture their experiences. Although interviews with Dukies and their parents were conducted and initially analysed separately, due to their complementary nature, they were drawn together in later stages of analysis and therefore presented together, rather than sequentially. Quotes from Dukies are identified with pseudonyms to facilitate confidentiality followed by the letter “D” for the Dukies. Equally, quotes from their parents are identified with pseudonyms followed by the letter “P” for parent. Additionally, some identifying words or phrases are left out or changed from quotes to ensure confidentiality is maintained. In instances where words have been left out, this is marked with ‘…’; and where words have been changed, the new word is placed within brackets [ ]. This is particularly important in this study given the small size of the neuromuscular community living in NSW and the even smaller group of young people who participated in this Award.
Initial Motivations: “Why We Decided to Do it”

Dukies and their parents discussed their reasons for deciding to do the Duke of Edinburgh’s Award. Dukies were motivated to do the Award in order to create future participation opportunities for others with neuromuscular disease. Both the Dukies and their parents repeatedly said that the opportunity for the Dukie to do new things and learn new skills was a motivating factor to participate in the Award. The parents interviewed were also drawn to the Award because it provided them with resources necessary to help Dukies to do new things and learn new skills. Also, it encouraged Dukies to experience life outside of home.

Wanting Other Kids to Have a Go

Dukies explained that they wanted to ensure that the Award could continue in the future for others with neuromuscular conditions. For some Dukies, this sense of altruism and responsibility for their peers with neuromuscular conditions was a motivating factor for choosing to participate in, and ultimately successfully complete, the Award. They described needing to set an example, and they recognised that they would play an important role in ensuring that the Award would continue to be offered in the future. They described a need to promote the idea that young people with neuromuscular conditions were able to engage in, and successfully complete, such a program. They described a strong sense of responsibility and desire to contribute to their community - other young people living with neuromuscular disease: “I just wanted to finish the pilot program to get it up and running for other kids.” Mark (D). One Dukie, Kristy, was aware that she was one of the youngest in the group piloting the Award. She recognised the important role she played in proving to the organisers of the Award that young people her age could also participate and successfully complete the Award:
“The knowledge that I was part of the pilot... so it was setting up for other kids to have the opportunity to do it and I was the youngest to do it so... I had to think of others not just myself: I thought what if there are other kids that wanted to do this and I needed to show that my age group can do it” Kristy (D).

**Opportunity to Do New Things and Learn New Skills**

The Duke of Edinburgh’s Award had not previously been available to young people with neuromuscular conditions; therefore, the novelty of the Award was what attracted them to consider participating. Dukie, Mathew (D) said: “I thought it would be a good program because you could do the stuff that you wouldn’t normally do and I liked that”.

Dukies felt that the Award would provide an opportunity to participate in new activities that the Dukies normally are unable to because of social and environmental barriers. These consisted of the family’s socioeconomic status, lack of appropriate transportation and access to the community, plus lack of appropriate programs and resources in the community. The Duke of Edinburgh’s Award was viewed by the Dukies and their parents as an opportunity to overcome these barriers. The financial support through MDNSW which funded Dukies’ participation in the Award was considered a great help by the parents, as discussed in more detail below. Dukies feared that the Award might not be available in the future, given it was a pilot. As a result they did not want to miss out on this potentially one-off opportunity:

“it was something different and it’s never been available to people who are disabled before so I thought that it would be a good opportunity to take because it might not get a second chance and it’s a pilot program” Samantha (D).
Dukies anticipated that they would develop new skills by participating in new opportunities available to them through the Award. Dukies felt that the Award would help them gain new skills for day-to-day life: “I needed to learn new stuff” Samantha (D).

Like the Dukies, parents also felt that the program would provide the Dukies with the opportunity to do new things and learn new skills. They explained that they tried to motivate their child to engage in the Award by highlighting the potential of developing new skills: “I said you can do it and you can learn a lot of things” Rebecca (P). Parents believed that participating in different sections of the Award would allow their child to learn new skills that are often not learnt at school. As a result parents felt that this was a valuable opportunity for their child: “She said she will be learning some skills… I though it’s a good idea because she can learn something new besides school” Joanne (P).

Resources to Help Dukies to Do New Things and Learn New Skills

A motivation only discussed by parents was access to valuable resources. Resources available through MDNSW, including financial support and support from staff organizing the Award, motivated parents to encourage Dukies’ participation in the Award: “They were going to support us… I thought if they did that then we were right to go… MDNSW helped with funding of the adventurous journey which was $10,000” Debbie (P). Many of the Dukies who participated in this research were from single income families. These families described the financial hardship they faced and their inability to fund a lot of extracurricular activities for their children. Parents explained that for the Dukies to be able to participate in the community, they required appropriate transportation, qualified caregivers and money since the costs involved for a disabled child to engage in community-based activities is typically much more than for a non-disabled child. Parents said that the financial support received through the Award meant that they did not
have to solely fund their child’s activities. This was described as a big help for many of these families and was a major motivating factor for parents: “I just said to him consider what has been offered to you... they get a certain amount of money to do these fantastic things...” Sarah (P).

**Dukie to Experience Life Outside of Home**

Parents also anticipated that the Award would encourage the Dukie to get out of the house and have normal teenage experiences. Some parents had heard about the Duke of Edinburgh’s Award before their child enrolled. When MDNSW introduced the Award to the parents, they described being delighted to hear that their child could take part in this pilot Award. Parents described the progressive nature of neuromuscular disease and witnessing over time their child spending more and more time at home. Parents spoke about the life-limiting nature of their child’s condition and their desire for their children to experience life to its fullest. To some parents, their children’s participation in the community was extremely important. For example Joanna, a parent, said: “I know her life is not that long, why don’t I let her experience more and something new besides the house”. Parents recognised that the Award would increase the Dukie’s social and community participation and, in doing so, alleviate the boredom the children express about being ‘stuck’ at home: “I don’t want her to stay at home and be like I don’t know what to do. It’s boring at home. It’s important to make friends” Rebecca (P).

**A Life Worth Smiling About: Experiences of Young People with Neuromuscular Disease Participating in the Duke of Edinburgh’s Award**

Dukies repeatedly described a number of changes they had noticed in themselves as a result of their participation in The Duke of Edinburgh’s Award. These changes were also identified by the parents and include:
• “I have achieved goals I set myself” (Sense of accomplishment)
• “Got me more independent, doing stuff for myself” (Learning independence)
• “It helped me communicate with others” (Social confidence)
• “I got to go out into the community” (Increased community participation)
• “I met someone else with the same disability that understands what it’s like” (connection and attitude towards disability)
• “I now know I can do pretty much everything… like everyone else” (Self-belief)
• “Thinking bigger and beyond the box… thinking wider and broader” (New outlook/perspective on life)
• Improvement in Dukie’s health

“I Have Achieved Goals I Set Myself” (Sense of Accomplishment)

The Dukies and their parents said that by engaging in The Duke of Edinburgh’s Award, Dukies were able to experience a sense of achievement and accomplishment. For some, this was the first time they had accomplished something that they, themselves, had agreed to participate in: “It felt good! Because that’s pretty much the first time I have achieved goals that I have set myself …” Jennifer (D). One parent reflected on her son’s experience at the Gala ball where he was presented with his award for completing the Duke of Ediniburgh’s Award. She highlights how proud he was for completing the Award: “To see his face at the Gala ball... He was just so proud of himself” Susie (P). Parents indicated that, at times, Dukies wanted to quit the Award as it was considered too difficult; however, encouragement from their family and friends and also perseverance on the Dukie’s part made them continue: “I think it’s a fantastic award because it shows perseverance. He could have given up if he didn’t persevere ... it taught him to try and stay consistent and if you say yes to something you keep going with it” Sarah (P). Parents also
felt that through the Award the Dukies were able to participate in activities that made them happy: “When he is off doing his Dukie stuff he is wonderful and he is inspired and he loves it”

Nancy (P)

“Got Me More Independent, Doing Stuff for Myself” (Learning Independence)

Dukies were required to independently plan, organise and execute their plans in every section of the Award. Dukies and their parents highlighted that through the Dukie’s participation in the Award, Dukies were able to learn new skills such as organising, planning, and choice making, all of which lead to becoming independent: “…the Duke gave me the idea of independence. When I was doing the Duke I realised that I wanted to be independent and I want to live independently” Samantha (D). One Dukie said that he is now more confident to organise things for himself: “I feel more confident on the phone now, organising stuff” Mark (D).

Some parents said that prior to the Award, the Dukie was heavily reliant on them and the rest of the family; however, the Award proved to the Dukie and their parent that they could in fact manage without their parents and become self-reliant:

“She is more confident and now if you ask her to do something like search through the net she knows how to do that. Before the Duke she would always say ‘Mum you do it for me’. I had to do everything for her or she had to wait for her sister or brother to help her…now she can plan and organise things for herself” Joanne (P)

The Award required Dukies to independently plan aspects of the experience including arranging caregivers to accompany them on their adventurous journey and choosing and planning their activities for each section of the Award. Dukies explained how, through this process, they developed organisational and communication skills: “I think with the Duke it’s very much about organizing things and it’s not just about doing it… I learnt to deal with people and
learnt to negotiate and compromise” Samantha (D). Some Dukies were able to transfer the skills they gained from the Award to other parts of their lives including planning family holidays. For some, this was the first time they were able to take part and assist their family. The Award reassured the family that the Dukie was more than capable. One parent spoke about the Dukie planning a family trip overseas after she had completed the Award. The Dukie had never done anything like this before:

“The Duke is very good, she learnt to organise everything... before she had never done that. We organised everything for her... she knows, now, how to organise and book things, talk to people and everything. I’m so proud of her” Rebecca (P).

Parents said that prior to the Award, they had been the ones responsible for the Dukies’ day-to-day planning. By participating in the Award, Dukies gained skills to do some of this planning themselves: “Learning how to plan carers and things [for adventurous journey] would help me in the future when I need carers for myself” Claire (D).

“He had to make a lot more decisions and planning... now he can organise a lot more things for himself. I have noticed a big difference and he is now able to organise his own appointments. It’s given them a lot of the life skills that once they leave school they don’t get the opportunity because we tend to do that for them. The Duke of Ed teaches them to be independent and they make decisions for themselves...” Susie (P).

“It Helped me Communicate with Others” (Social Confidence)

Dukies and their parents recognised a change in the Dukie’s confidence in social settings, particularly an enhanced confidence in their ability to communicate with others: “I’ve noticed that I have become more confident especially in communicating with people and that’s been a big area of improvement for me” James (D). For some Dukies, the Award helped build social
confidence by encouraging Dukies to interact with people outside of the family: “It’s [Duke of Edinburgh’s Award] helped me communicate with others because I haven’t been big on communicating to people. I am not a big fan of people sometimes” Kristy (D). Parents also noticed this change in the Dukies and often referred to their increased confidence in engaging socially with people outside of the immediate family:

“He has been able to deal with people and meeting people for the first time a little bit better. I feel his self-esteem seems to be a little bit better. I have noticed the difference… when he talks to someone he will look at them now whereas before he would have his head down” Susie (P)

Dukies and their parents highlighted that, prior to their engagement in the Award, a lack of confidence limited Dukies’ social interactions. Parents described the Dukies as being previously shy, and at times withdrawn, in social contexts: “She was shy before the program and when we went to places she would always say ‘mum you talk to them’...” Rebecca (P). Prior to the Dukie’s participation in the Award, some Dukies lacked social skills according to their parents. One of the parents, Joanne, described a dramatic shift in her daughter’s social confidence since participating in the Award:

“Before the program she was timid. Sometimes we asked her to go and talk to someone and she was saying ‘I don’t know how to start a conversation’ but now she can do whatever she likes and she socialises with friends and people she has never met before” Joanne (P)

“I Got to Go Out Into the Community” (Increased Community Participation)

According to both the Dukies and their parents, the Award increased the Dukies’ level of activity and engagement within the community: “I did all these things that I never experienced
in my life” Mathew (D). For some, this was the first time that activities were set outside of the regular school and home environment: “the Duke is so important because I got to go out into the community instead of just school and home” Jennifer (D). Parents were often worried about their children being at home and therefore really valued the fact that the Award encouraged the Dukies to go out into the community: “It was a great experience for [Dukie] because it got her out there” Madeline (P).

Parents also felt that the Award encouraged Dukies to develop age appropriate skills and engage in age appropriate activities. Parents explained that community-based experiences which are considered to be a normal part of a teenager’s life such as playing sport, driving, dating and going out in the community are challenging for their children. Parents described trying their best to normalise life as much as possible for their child and praised the Duke of Edinburgh’s Award for giving their children an opportunity to engage in activities that are age appropriate. For example, Debbie explained that through the Award, her daughter was able to experience a modified version of ‘schoolies’. ‘Schoolies’ is an end-of-high-school celebration where young people go on vacation with a group of friends to mark the end of the schooling milestone.

“Everyone gets the opportunity at her age to go and do things .... all her friends went to do schoolies but she is just not part of it. To me, her going off and having [friend] there, it’s not the same thing but it’s as close as we are going to get to it” Debbie (P).

“I Met Someone Else with the Same Disability that Understands What it’s Like”

(Connection and Attitude Towards Disability)

Many of the Dukies described building on existing relationships with other peers with a disability and developing new relationships through their experience of The Duke of Edinburgh’s Award: “I have made friends with a few of the other Dukies. The
communication is on Facebook generally but it’s good to get to know different people”

Kristy (D). Seven out of the eight Dukies interviewed relied on power wheelchairs for mobility. These individuals described the importance of developing friendships with other Dukies who were wheelchair users and therefore in a similar life situation, especially in regards to accessibility:

“It was good because I had met someone else with the same disability that understands what it’s like. Most of my friends at school are all abled bodied so it is good to know someone that understands…. with [another Dukie], when we go to places we don’t have to worry about asking if places are wheelchair accessible but with my other friends if I am invited to parties I have to make sure it’s all wheelchair accessible so I can get in

Jennifer (D)

Some Dukies discussed their hesitation in meeting others with neuromuscular conditions prior to their enrollment in the Award. One Dukie had not wanted to associate with people with a disability prior to his participation in the Award. However, after meeting other young people with disabilities who were doing the Award, he described how he related more to them than his non-disabled friends at school:

“I never used to be the one who would like to meet people with disabilities. I don’t know whether it was because I had my disability and that was enough for me and I didn’t want to broach the subject or because I thought I wouldn’t like them or that I wouldn’t be accepted by my other friends [abled bodied]...I always used to like to be with my friends at school and I didn’t want to meet other people with disabilities but since I have been doing the Duke of Ed and meeting a lot of people with disabilities I have realised how good they are as people and how valuable they are as friends... I actually prefer
them to my abled-bodied friends, which is a massive step in my life. They just understand me more and I don’t feel like the odd person out. You feel more accepted”

James (D)

The Dukies also provided insight into the benefits of the Award for these young individuals in relation to their acceptance of others with disabilities. Dukies reported a shift in their acceptance of others with a disability when they met and shared experiences with others who were also going through a similar journey: “Just having the common experiences... common hospital frustrations... we can sympathise with each other’s situation and the frustration of not being able to get to the shop and dealing with naïve people” Kristy (D). Parents equally described the benefits of Dukies being able to network and build friendships with others with a disability, which helped them realise that there are others experiencing similar life situations: “It certainly has opened him up to people in wheelchairs and that has been good for him” Sarah (P).

In contrast, Dukies described their non-disabled peers at school as lacking insight into their lives and the challenges that people with disabilities face on a daily basis. Things that their peers take for granted are often things that they find difficult. Dukies explained that at times they find it difficult to contribute to peer conversations at school and to relate to their non-disabled peers:

“I find the relationships with my non-abled bodied friends to last longer because we are not as shallow as some of my [abled bodied] peers... when it comes to my situation theirs isn’t bad. I have a wheelchair that’s a big deal whereas if they have a pimple on their face that’s a major deal. I get very frustrated unfortunately with my peers at school because they are interested in things like what they look like and there’s more to life than that. Their interest is not the same” Kristy (D)
“I Now Know I Can do Pretty Much Everything… Like Everyone Else” (Self-Belief)

Dukies and their parents described a shift in the Dukie’s attitudes and beliefs about themselves following participation in The Duke of Edinburgh’s Award. They repeatedly described an increase in the Dukie’s self-belief as a result of their participation. The Award enabled Dukies to realise that despite their physical restrictions, they were able to achieve and succeed like everyone else:

“…The Duke makes me feel like I am not limited with my disability. There are a lot of things that I can’t do but the Duke makes me feel like there is nothing I can’t do. I can do pretty much everything like everyone else and succeed like everyone else” Jennifer (D)

Dukies described a shift in attitude from “I can’t” to a more driven and strength-focused attitude of “I can”. The Award gave the Dukies insight into their abilities and skills and encouraged them to have a go at things, which they had previously considered impossible to attempt:

“I feel more ready to face things and I feel like now that I have done the [Duke of Edinburgh’s Award], I can do so much more than what I said I couldn’t do… It [Duke of Edinburgh’s Award] has encouraged me to have a go at different things that I might not have been willing to have a go at previously” Kristy (D).

Parents also felt that The Duke of Edinburgh’s Award had given the Dukies an insight into their own potential to set more ambitious goals and achieve these goals: “It’s [Duke of Edinburgh’s Award] opened her world up to her abilities… Now I am a little bit nervous about what lays ahead. She is thinking wider and broader” Jan (P).
Parents emphasised the value of the adventurous journey component of the Award. They stressed that it was the adventurous journey that enabled the Dukies to start to believe in themselves. It changed their outlook on life and brought back excitement in their lives: “When [Dukie] went to the [adventurous journey] last year he came back so excited and so good and his whole demeanour had changed” Nancy (P). When one parent was asked if she had noticed any change in her daughter as a result of her participation in the Award, she replied: “Yes! Confidence wise yes! That she can actually push herself to do something if she chooses. Maturity, definitely! Organisation, definitely!…” Jan (P).

This attitudinal shift of “I am capable” resulted in Dukies setting more ambitious goals to achieve in the short term but also envisioning what life could be like in the future and having a new outlook and perspective in life.

“Thinking Bigger and Beyond the Box… Thinking Wider and Broader” (New Outlook/Perspective in Life)

Some Dukies considered the Award to be life changing for them; and despite being challenging at times, they believed the Award changed them as a person. For example, Dukie Kristy said that engaging in the Award is: “worth all the challenges. You come out of it a different person and having a different perspective. It’s definitely worth doing” Kristy (D). Some Dukies became more ambitious in life; and after participating in the Award, they began to seek new opportunities: “Now, I just like going out and exploring new things and meeting new people” Jennifer (D).

For many of the Dukies travelling, and particularly travelling without their family, was considered too difficult or impossible. However, Dukies and their parents indicated that once the Dukie had completed the Award and successfully completed their adventurous journey, they had
a new-found confidence and were able to set travel-related goals for their future. For example, one Dukie described his travel hopes and dreams for the future: “I want to go to America and do a Contiki tour and I want to do a Europe tour with my mates and I will probably do that sometimes later in my life on my own. I just want to travel” Mathew (D). Parents said that participation in the Award encouraged Dukies to see beyond their disability and not to limit their dreams due to their physical disability. One parent said that her daughter had previously put herself “in a box” and highlighted that the Award gave her a new outlook in life to try and “expand that box”:

“[Dukie] puts herself in a box. She knows what she is good at and she does what she is good at but beyond that she can’t imagine what she can do and that’s what the Duke did. It made her think bigger and beyond that box. It gives the children the opportunity to expand that box that will become a natural part of their disease... what the Award does is put all of life experiences into one program because their life is very limited and they don’t have a life time to figure all of this out...” Debbie (P)

Another parent, Jan, described her daughter’s view on life prior to The Duke of Edinburgh’s Award in contrast to after she had completed it:

“In a shell or in a cave, a cave a dark cave. No direction, lack of motivation, just down, nothing to look forward to. By doing the Duke she thinks anything is possible. She is talking about moving out of home, she is talking about moving to other states and starting on her own... she is thinking wider and broader” Jan (P)

**Improvement in Dukie’s Physical Health**

According to parents, The Duke of Edinburgh’s Award not only impacted on the Dukie’s psychological well-being and sense of self, but it also had a positive impact on their physical
health. One parent spoke about her daughter learning how to float as a result of the fitness component of the Award: “I like swimming because it’s good for her to move around. Before she didn’t float very well and now she can” Rebecca (P). This was particularly important for this Dukie, since stretching in the water and swimming are the only forms of exercise she can participate in due to severe mobility restrictions. Through this engagement in the fitness component of the Award, Dukies were able to achieve great health benefits:

“I think it has been extremely positive... she has gone to physiotherapy [as part of her fitness section of the program] which has straightened her legs 32 degrees... she can now almost straighten her legs. I feel she has gotten stronger in her hands” Madeline (P).

Interestingly, Dukies did not talk about the physical health outcomes of their participation. This seemed to be a priority for their parents rather than the Dukies themselves.

Letting Go: Experiences of Parents of Young People with Neuromuscular Disease Participating in the Duke of Edinburgh’s Award

Parents spoke about their personal experience of having their child participate in the Duke of Edinburgh’s Award. Parents described their own process of learning to “let go”. They spoke about their struggle to let go, as well as ultimately recognising the benefits of letting go for their child. Additionally, parents said that they were able to get respite from their role as caregivers when their child was participating in the different sections of the Award.

Letting Go

Parents repeatedly spoke about the Award encouraging, or perhaps forcing, them to learn to let go. Letting go in this case meant that parents were required to support and encourage their
child’s participation in the different sections of the award and promote independence. Parents described that they were required to emotionally and physically distance themselves from their child. Parents described the emotional challenge involved in letting go of their child, particularly during the adventurous journey component of the Award. The Award required Dukies to take part in an adventurous journey in which they spent a period of time away from, and out of contact with, their family. It was expected that during their adventurous journey, their caregiver was not a family member. Despite their own struggles to let go, parents were ultimately able to realise the importance of letting go and the benefits this had on their child.

**Struggle of letting go.**

For many of the parents, the internal struggle of wanting their child to be independent, but protected at the same time, meant that they were initially anxious about the adventurous journey: “To know that I was putting my daughter in the care of others overseas and a lot of distance between us... I definitely didn’t handle it” Jan (P). Trusting another person whom they might not have met previously to look after their child with a disability was a frightening thought for many parents: “When I heard about the adventurous journey component of the program I was shocked! But when I was assured that the carer was reliable, trustable and she has a lot of experience as a carer I said OK” Joanne (P). Parents were anxious at the thought of their child not being by their side. At times, parents indicated that their role as a caregiver of their disabled child was what defined them as a person. Parents also discussed the fact that their child was at the centre of their world and everything they did revolved around this individual; therefore, parents discussed feeling a sense of loss. Since their child partly defined who they were, they struggled to fill up the time when their child was not with them; and they were unsure how to fill up their time:
“I just stay[ed] at home and didn’t know what to do. She is always with me all the time since she was born and so I always have someone there to take care of and when she went on her adventurous journey I sat there and didn’t know what to do and no one to talk to” Rebecca (P).

No contact - difficult but important.

Dukies, who were accompanied by paid caregivers were expected to not make contact with their families for the duration of their adventurous journey. This was a requirement of the Award. However, there appears to have been some inconsistency in how this was adhered to in practice. Some formal caregivers, that is, caregivers funded through the program, permitted contact between the Dukie and their parent during the adventurous journey; while other caregivers restricted family contact. Parents said that the limited contact they had with the Dukies placed them under extra concern and stress:

“I wanted to call her but they said you can’t call her and this part I didn’t like. I was worried especially at night. One night I called her and she was like ‘oh mum don’t call’ and the carer screamed ‘no calling’... I think people when the child is normal they can do whatever they want but with people with a disability the mum is worried about them so they should let them call. I wanted to make sure that she was OK” Rebecca (P)

Parents claimed that contact with the Dukie was to ensure that they were in good health and to give the parents some peace of mind. Parents spoke of the struggle with transitioning from the full-time caregiver to then having no contact with their child:

“I think it’s important for the parents. I don’t see why you can’t send a text to say hey how was your day? How is the accommodation? Because you know you are very involved in their lives and I wouldn’t like it if I couldn’t contact him” Susie (P)
One parent said that she only wanted to be contacted in the case of an emergency. Her goal for her children was for them to become independent, and she viewed the no contact rule as an opportunity to teach the Dukie to become more independent:

“...limited contact is fine as long as if something goes wrong that I am notified. I suppose the best thing I can imagine for my kids is to become independent and not need me anymore. I don’t want to be needed” Sarah (P).

Majority of the parents (n=6) discussed their distress and sometimes anger about the no contact rule while the Dukie was on their adventurous journey. They emphasised the importance of contact to reassure that their child was safe. Parents emphasised that putting their child in another person’s care was a big adjustment. As a result, anxiety levels were high for the six parents who were not accompanying their child on their adventurous journey. One parent compared letting go to losing someone and the grief associated with this:

“... nobody understands that if you look after someone 24 hours a day 7 days a week, of course the carer is going to think ‘are they OK?’ How dare they not be able to give a phone call? Just for peace of mind. When you’ve got a child born with a disability they become your life. You don’t have another life and you can’t imagine having someone else walk in and say you don’t count anymore, your invisible and I am taking over now. People have no idea how hard it is to let go. It’s a big adjustment. It’s the same as going through a grief; it’s like losing someone. It’s a big loss and it’s a big worry” Madeline (P).

Despite their anxiety about the no contact rule, some parents recognised the importance of limited contact during the Dukie’s adventurous journey. They felt that it allowed their child to
become more independent and less dependent on the family: “I tried not to interrupt so I texted him once a day because it’s important that they feel like they have independence without us bothering them” Susie (P). Another parent said she tried to limit the contact during her child’s adventurous journey as she realised that this was her child’s journey and wanted her child to know that she could cope with the separation:

“[No contact during adventurous journey] was good in itself to show her that she can do it… I sent her an email just to let her know that we were thinking of her. But it was up to her if she needed me. It’s her journey I needed to let her go” Jan (P)

Learning to let go.

Through their child’s participation in the adventurous journey section of the Award, parents became aware that their child could cope without them and also achieve independence. As a result, parents described realising that they too could cope and let go of their child whom they had been previously holding onto tightly and protecting so closely:

“Normally with kids who have a disability the parents wouldn’t let them go out with a carer. They always look after them but with this program they had the opportunity to be independent and to experience the outside world… when she went away [adventurous journey] which she had never done before, we could never imagine we could let her go with a carer. It was a big decision for us… After she participated in the Duke of Ed I was OK to let her go with her friends… I think I need to let her have more time to experience the outside world without me by her side. I think it’s good for her to be like normal kids and that’s why I let her go” Joanne (P).

Recognising the importance of letting go.
Despite reporting their struggles and resistance to letting go, majority of the parents indicated that, after their child’s completion of the Award, they recognised the importance of doing so. Majority of parents agreed that it would be detrimental to the Dukie’s quality of life to keep ‘holding on’ to them because of their own concerns and feelings. By being able to let go, parents recognised that they were more able to promote choice, resilience and independence:

“...The adventurous journey on his own, separate to me has been really good for him... to go out there on his own and that he can survive without me” Sarah (P).

“Clinging on to them is the cruellest thing you can do... how are they ever going to experience what it’s like to be an individual if they are not allowed to be an individual... let them experience life and they’ll have tough times and they probably will have a cry but they will work it out” Madeline (P).

Most parents also recognised that projecting their own fears onto their child and not allowing them to participate would be more harmful and limiting to their child:

“Don’t hold your child back, don’t anchor them, let them fly, give them wings, encourage them to do it, let them go. This is their journey, let them have one, its memories, its growth, it’s opening up their world to their potential... What right do we have as a parent to hold our children back because we feel insecure or unsafe? Why put our insecurities or our fears on to them” Jan (P)

“I Just did my Own Thing Because I Don’t Get That Very Often” (Respite)

While most parents described initially feeling lost, they highlighted that as a consequence of their child’s participation in the Award they were able to get some much-needed respite. Parents described the benefit of having some respite while their child participated in the Award in particular when the Dukie was away on their adventurous journey. Some parents spoke about
spending time with their other children while others took advantage of this time and went travelling: “The first time she went away [destination of Adventurous Journey], we went away too at that time. I went to [Australian state] to visit my son who is studying there” Joanna (P).

Others described being able to just have a break and to re-energise for when their child returned to their care: “We went to the beach for the week up the coast... I just wanted to sleep and let my body heal... we got to do a few things that we don’t normally do” Jan (P).

Parents took advantage of the break and did the things that they wouldn’t normally do when the Dukie was at home: “I just did my own thing because I don’t get that very often” Sarah (P). Many Parents said this was a very new experience and some had never had the opportunity to spend time away from the Dukie: “…it was lovely to be able to go for walks and things that we don’t normally do when he is there” Susie (P).

**Components that Enhanced Participation**

Through the interviews with the Dukies and their parents, a number of essential components that enhanced their participation and led to the success of the Award were described. These essential ingredients were i) choice ii) level of challenge, and iii) access to resources. It was these essential ingredients that enriched the Dukie’s experience of the Award.

**Choice**

Interviews with Dukies and their parents’ highlighted that choice is a key ingredient in the Duke of Edinburgh’s program. There were a number of aspects in the Award that led to Dukies making independent choices: choosing their activities for each section of the Award, choosing when to participate in their activities, choosing which section of the Award to complete at any given time, choosing the destination for their adventurous journey, choosing the carers to accompany them, and finally, choosing whether or not to continue the Award. All these factors along with
supportive paid carers and the ability of parents letting go led to Dukies making independent choices.

Initially most parents gave the Dukies the choice to participate in the Award: “So I said to her have a good think about it. Come up with a few strategies. What are some of the things you might want to do?” Debbie (P). However it is important to highlight that some Dukies felt that their parents tried to influence their choice and therefore becoming a barrier to their participation. Families were cautious and concerned about their child’s physical and emotional health when making decision in terms of activities for their child to participate in. One Dukie reflected on her choice of adventurous journey and mentioned that her family were anxious and worried about the adventurous journey and wanted her to choose a “safe option”:

“Prior to my trip they [family] wanted me to change the place I was going to but I decided to go ahead with my plans. I think they were worried and wanted me to go somewhere closer. Prior to my trip they were really worried.” Jennifer (D).

Parents described their own anxiety about their child’s participation in the Award, in particular the adventurous journey. This anxiety often influenced how flexible they were in allowing their child to engage in the Award and the type of activities they were willing to allow their child to do. During the interview with one parent she mentioned that she had expressed to her daughter that she needed to plan a trip within Australia and not overseas: “I told her not too far so she said maybe inside Australia not overseas” Joanne (P). Parents said they were very cautious of the impact of the Award on their child and some did not feel that the Award was a priority compared to other aspects of their child’s life such as school:

“She is a good girl, everything that she wants to try she asks me. She is not just doing it. She knows that I am worried about her ... She doesn’t argue with me or
anything like that… [Dukie] is in university that’s why she didn’t continue because she is busy. She likes to do [Gold award] but she is too busy. I don’t want her to be so tired” Rebecca (P)

Despite at times becoming barriers, parents felt that they played a very important role in the Dukie’s experience of the Award: “I am forever coming home saying come on there is a new thing out and I want you to do it and I think it would be good for you… I have always had to push him along” Sarah (P). Parents were often the individuals who supported and motivated the Dukies through the experience: “I’ve always taught her that if it doesn’t happen as a normal person does, there’s got to be another way. You still will make it happen; it just won’t look the way you thought it might look” Jan (P). Another parent described how she supported her daughter to continue the Award and not give up: “She was ready to pack it in and throw it all away and I was like “no you are not!” Jan (P). One parent highlighted the important role parents’ play and the sacrifices they need to make in order to enhance and enable their child’s participation:

“She can only access this stuff if I am prepared to commit as well because she depends on me. She can come up with the ideas… but at the end of the day for it to actually come about is for me to help her access the people, communicate with the people and make it actually all come together… I walk the road with her and give her the opportunity” Debbie (P).

Dukies also spoke about the support they received from their parents. Dukies indicated that when aspects of the Award were too difficult and they felt like quitting their parents supported them and encouraged them to stay on task: “At one stage I came close to quitting. I
was like I can’t do this it’s too much but Mum and I sat and broke it down into little bits, it looked more manageable and I decided to continue” Kristy (D).

After completing the Award many of the Dukies discussed feeling confident in making their own choices. Dukies spoke about the importance of making independent choices and having control in their lives. Many talked about their desire to be respected as individuals and as an adult: “Patronisation is my worst enemy and so many people including carers talk in a patronising tone without realising. They just talk to you like you’re a child” Melissa (D). One Dukie spoke about wanting her paid caregivers to understand and respect her as an adult and to only provide practical support. This Dukie is reflecting on her adventurous journey where she was accompanied by paid caregivers organised through the Award:

“They would basically be your arms and legs to help you with things not so much telling you what to do. Listen to what we want and not baby us... they were telling me what to do even though it was supposed to be an independent thing” Claire (D).

Challenge

In addition to choice, challenge is another important ingredient in the Duke of Edinburgh’s Award. Parents and Dukies described the importance of Dukies being pushed outside of their comfort zones and learning new skills at the same time.

Parents felt that the Duke of Edinburgh’s Award would give their child the opportunity to experience a life outside of the home and experience challenge. Some parents praised the Award for allowing their children to experience some challenge: “The Duke of Edinburgh’s Award is giving them something that school doesn’t... they need to be pushed a little bit” Susie (P). Dukies and their parents repeatedly mentioned the importance of engaging in new experiences, developing skills and being pushed out of their comfort zones, while participating in the Award.
Parents indicated that activities needed to have an element of challenge in order to attract the Dukie’s interest:

“[Dukie] picks things that are way harder than they need to be but that’s who she is. If it’s just to comply then she would kind of go there is really no sense in doing it because it’s not really offering me anything… there are lots of things that she can do but it’s not challenging... Unless it’s creating a challenge it’s not worth even doing…The thing is she wants to do the big stuff because that’s challenging” Debbie (P)

Dukies and their parents highlighted the importance of activities having an element of challenge: “It was a good way to get my mind active and thinking about different things” Kristy (D). In contrast, when the activity was not challenging enough the Dukies reported getting bored and wanting to give up. For example one Dukie reflected on the volunteering component of the Award and said: “[volunteering activity] was alright at first and then it got a bit boring... If I am not learning anything then I am like what’s the point and I want to give up” Mathew (D). Dukies also spoke about not always liking challenge in the moment however on reflection they appreciated having the challenge and realised the importance of just right challenge: “Although it’s a bit of a struggle to organise things and do the paperwork, it’s good and it’s really important and I would do it again and again. The experiences and the people you meet are brilliant” James (D). Other Dukies complained about the planning phase of the adventurous journey as it was too challenging for them, however they said they enjoyed the actual journey: “During the planning phase there were days I just didn’t want to do it but during the actual journey I didn’t want to quit” Melissa (D).

Parents also spoke about Dukies becoming competitive during the Award in particular during the fitness activity and also competing against other peers who they met through
Muscular Dystrophy NSW and were also participating in the Duke of Edinburgh’s Award.

Parents embraced this competitive element of the Award, indicating that competition encouraged the Dukie to take on the challenges in the Award and to push through the Award and achieve more: “[Dukie] has been seeing what [other Dukie] has done. The competition is there and they don’t have that normally and that’s a good thing and it gives them a drive” Susie (P). This parent reflects on her child’s efforts during the fitness component of the Award and highlights the importance of having competition to push themselves to achieve: “…something clicked in her somewhere to challenge herself to do better…There was a bit of family competitiveness coming out so that ignited something in her to do better and to challenge herself” Jan (P)

Access to Resources and Support for Parents

Another important component of the Award, repeatedly highlighted by parents was access to resources through the Muscular Dystrophy NSW. These resources, including financial support, and guidance from the coordinator of the Award not only enabled Dukies to participate in their chosen activities within the Award, it also enabled a wider range of choices and thus more challenging experiences. By having these resources available to them, Dukies were able to choose activities that were of interest to them and they did not have to worry about the financial costs nor worry about issues with accessing an activity. Dukies highlighted that the resources from the Award enabled them to participate, just like any other person, in activities which, they had chosen and enjoyed: “the opportunity to do things we normally wouldn’t do, to be given the opportunity to do what everyone else does, just slightly modified” Melissa (D).

Parents referred to the financial support they received through the Award, which enabled their children to choose activities, which appealed to them and matched their interest and skills. This alleviated the potential financial burden and stress for the family: “Financial support has
been a great help for me to get the activities financed. The program pays for activities that I would normally have to pay for” Sarah (P). Parents also mentioned how the Award gave the Dukies access to a range of more stimulating or challenging activities, not normally available to them due to financial costs involved and lack of accessible programs. For people living with a disability, lack of appropriate access and resources in the community can limit the Dukie’s participation: “Now she is interested in wheelchair soccer but we have to pull a team together to do it from here it’s quite difficult” Debbie (P). Parents residing in the rural areas of NSW described the difficulty in accessing appropriate activities due to the lack of availability of activities which suit the needs of individuals with a disability and also the increased costs of engaging in any activities that were available due to limited access to public resources or services in rural areas:

“Here in the country you can’t just get a bus. There is one wheelchair bus and it does only one run a day so she can’t just go and catch a bus. She can go and catch a taxi but instead of paying a $5 fair she will be paying $40 to go into town. You’ve got that isolation unfortunately” Jan (P)

Dukies and their parents repeatedly highlighted that the most difficult aspect of The Duke of Edinburgh’s Award was the administrative tasks, including the planning of the adventurous journey, and the ongoing weekly online updates on the Duke of Edinburgh’s Award website:

“Probably the planning of the adventurous journey and then things like allocation of funds and how you were going to get there and whose going to look after” Claire (D). Often parents needed to contribute and assist with this, which they described being very demanding or onerous:

“...the biggest drama was the preparation for the adventurous journey. That was a huge amount of work and I ended up doing most of it because it was difficult. I had to help [James] a lot”
Sarah (P). Parents were often the ones providing much of the administrative support to the Dukies and they often struggled with how much support they needed to give to the Dukie without interfering with Dukie’s choice and challenge and how involved they needed to be in the Award:

“...to him it’s homework and that’s the last thing he wants right now so that’s a big push... we as parents are joined at the hip to them so we end up taking over a lot of the tasks and they are not like a normal child” Sarah (P).

Upon reflection on the experience one parent said that she feels she should have done more of the planning work, as it would have been a smoother process:

“I felt like I should have done a lot of it... it would have run smoother if I had taken a more active role. I don’t think I put enough time in there at all and I don’t think [Kristy] did either. The planning for the adventurous journey was a learning curve for both of us. She was thinking she was done but I wasn’t in the know enough to say no you need to do this, this, and this” Jan (P)

Parents and Dukies had a number of ideas in regards to how the Dukies could be better supported with the administrative side of the Award to lessen the burden on the parents. They thought the organisers of the Award at MDNSW could improve the Award by creating some form of a checklist: “A task checklist at the beginning would help. Having a task list of what needs to be done, simplifies it and you’ve got a simple visualisation of what comes next” Jan (P). They believed that this checklist would simplify some of the administrative and planning of the Award: “Anything that could make it a bit easier would be good. Like a standard or expected replies to actual questions because some are very vague” James (D)
Parents also recommended regular follow-up and support from Award coordinators:

“Coordinator to follow through from start to finish to see how they are going and see what they
are struggling with?” Jan (P). They believed that this would ensure that the Dukie stays on task
and will relieve some of the stress and pressure on the parents.

Parents explained that the senior years of high school is a very stressful period of the
Dukie’s lives. As a result the Duke of Edinburgh’s Award added extra pressure on the Dukie.
One parent felt that doing the Duke of Edinburgh’s Award in the senior years of high school is
not appropriate: “Part of me thinks that definitely year 11 don’t do it. Year 11 work is just full
on. That last week [before her adventurous journey] was a nightmare and she had assessments
and all that due as well” Jan (P). Dukies and their parents also commented on the level of
support required for Dukies who have other commitments which clashed with the Award such as
school and university commitments: “Doing my year 11 throughout the Duke was challenging. It
was around assessments and for that reason I won’t be continuing my Duke award this year but I
am hoping to continue next year once school is over” Kristy (D).

Summary

This chapter presented the results following the thematic analysis of interview data
collected from Dukies and their parents. The results highlighted the impact of the Duke of
Edinburgh’s Award on Dukies and their parents and the essential ingredients to the success of
the Award required. These findings will be discussed in the next chapter and implications for
practice will be proposed.
CHAPTER FIVE - DISCUSSION

This research explored the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award. Semi-structured interviews were conducted with Dukies, eight young people with neuromuscular disease who were participating in the Duke of Edinburgh’s Award. Parents were interviewed separately. This discussion chapter begins with a brief overview of the aims, followed by a summary of qualitative findings. Findings are then discussed in relation to the literature, particularly a model of participation proposed by Kang and colleagues (2014). Finally the limitations of this study and implications for future research will be discussed.

Overview of Central Aims and Purpose of the Thesis

This study explored the participation experiences of young people with neuromuscular disease who participated in the Duke of Edinburgh’s Award program administered by Muscular Dystrophy Association of New South Wales (MDNSW). The aims of this study were to:

a) Explore the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award;

b) Explore the experiences of parents whose child was participating in the Duke of Edinburgh’s Award;

Summary of Qualitative Findings

The central themes from this study were:

Initial motivations: “Why we decided to do it”

- Wanting other kids to have a go
- Opportunity to do new things and learn new skills
- Access the resources to do new things and learn new skills
• Dukies to experience life outside of home

A life worth smiling about: the experiences of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award

• “I have achieved goals I set myself” (Sense of accomplishment)
• “Got me more independent, doing stuff for myself” (Learning independence)
• “It helped me communicate with others” (Social confidence)
• “I got to go out into the community” (Increased community participation)
• “I met someone else with the same disability that understands what it’s like” (connection and attitude towards disability)
• “I now know I can do pretty much everything… like everyone else” (Self-belief)
• “Thinking bigger and beyond the box… thinking wider and broader” (New outlook/perspective on life)
• Improvement in Dukie’s physical health

Letting go: The experiences of parents of young people with neuromuscular disease participating in the Duke of Edinburgh’s Award

• Letting go

• “I just did my own thing because I don’t get that very often” (Respite)

Components that enhanced participation

• Choice
• Challenge
• Access to resources and support for parents
Conceptualisation of Optimal Participation

Kang and colleagues (2014) developed a conceptual model of optimal participation in recreational and leisure activities for children with physical disabilities, detailed in Chapter 2 (Figure 1, page 15). This model provides an evidence-based framework to assist professionals in the planning and facilitation of quality participation for children and young people. Thus, using this framework assists in understanding the complex interplay between child, family and environment. In this model, Kang and colleagues (2014) conceptualised optimal participation as involving the dynamic interaction between dimensions and determinants of participation. Kang and colleagues argue that the continuous experience of optimal participation has long term benefits for quality of life, and health and wellbeing.

The current study findings mostly align with Kang and colleagues’ (2014) model and add a richer understanding of participation experiences specific to young people with neuromuscular disease participating in the Duke of Edinburgh’s Award. However, the presence of challenge was an important factor in the dimension of self, in this study, which is not represented in Kang and colleagues’ conceptualisation. Furthermore, the findings from this study highlight the importance of parents letting go in order for their children to experience optimal participation. In the tables and paragraphs to follow, the findings of this study have been compared and contrasted to Kang and colleagues’ (2014) model. Findings which have been specific to this study and are additions to Kang and colleagues’ model are marked with *.
Dimensions of Participation

Dimensions of participation include physical, self and social engagement (Kang et al., 2014). These three dimensions are internal attributes or preferences of the young person which influence their participatory experience. Table 5 outlines the dimensions of participation outlined by Kang and colleagues’ with comparison to findings from the current study.

Table 5

*Dimensions of Participation: Comparison of Findings with Kang and Colleagues' (2014) Model*

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Description</th>
<th>Examples of participant’s quotes and broader themes from current study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Doing the activity</td>
<td>“I got to go out into the community” (Increased community participation)</td>
</tr>
<tr>
<td>Self</td>
<td>Enjoyment</td>
<td>Access to resources and support for parents</td>
</tr>
<tr>
<td>Self</td>
<td>Self determination</td>
<td>Choice</td>
</tr>
<tr>
<td>Self</td>
<td>Self-understanding</td>
<td>“I now know I can do pretty much everything… like everyone else” (Self-belief)</td>
</tr>
<tr>
<td>Self</td>
<td>Challenge*</td>
<td>“I have achieved goals I set myself” (Sense of accomplishment)</td>
</tr>
<tr>
<td>Social</td>
<td>Interpersonal</td>
<td>“I met someone else with the same disability”</td>
</tr>
</tbody>
</table>
Physical

Physical engagement refers to the act of *doing* the activity (Kang et al., 2014). Kang and colleagues emphasise that children with disabilities have a desire to be actively involved in an activity and not just physically present. In the current study, Dukies and their parents did not specifically refer to this ‘act of doing’ the Award; however, they spoke in detail about the Award process facilitating Dukies’ participation in the community. This was reflected in the theme: “I **got to go out into the community**” (*Increased community participation*). Most of the activities required Dukies to physically access the activity within the community, outside of the family home. It was reported that the support received from their parents, who provided the transport and physical assistance, as well as financial support and guidance from MDNSW facilitated their physical participation. This highlights that despite the Dukies’ significant physical limitations, the physical barriers were overcome with the right supports.

Self

Self-engagement according to Kang and colleagues (2014) refers to a child’s enjoyment, self-determination and self-understanding resulting from their involvement in an activity. Dukies and their parents reported that Dukies experienced major transformations in this dimension of the self. The findings of the current study reflect the three aspects of the self, described by Kang et al.
However, in addition to the three elements described by Kang et al, the element of challenge was integral to the dimension of self. Below are illustrated findings from the current study applied to the model with the addition of challenge.

**Enjoyment.**

Kang and colleagues (2014) indicate that enjoyment is a positive experience resulting from participation. It is believed that enjoyment is a motivator for selecting and continuing to participate in an activity (Allender et al., 2006; Barletta & Loy, 2006; Hohepa et al., 2006; Specht et al., 2002). Results of the current study support Kang and colleagues’ (2014) claims about the importance of enjoyment and are echoed in the theme ‘Access to resources and support for parents’. In this study, Dukies were encouraged to select activities based on their own interests and abilities. Dukies highlighted that the resources through MDNSW and support for their parents enabled them to participate in activities they had chosen and enjoyed. The Dukies and their parents identified enjoyment of activities as a motivator, encouraging Dukies to continue their participation despite experiencing some challenges during their experience.

**Self-determination.**

Kang and colleagues (2014) suggest that self-determination can be increased through choice and control of activities of interest and experiencing the effects of these choices. The importance of choice is also reflected in this study. In addition to choice, the study findings also bring attention to the importance of independence for self-determination. Independence is an addition to self-determination in Kang and colleagues’ (2014) model.

Dukies were encouraged to make a number of choices, throughout their enrolment in the Duke of Edinburgh’s Award. These include:

- Choosing activities for each section of the Award
• Choosing when to participate in their activities
• Choosing which section of the Award to complete at any given time
• Choosing the destination for their adventurous journey
• Choosing the caregivers to accompany them
• Choosing whether or not to continue the Award

These choices, as well as support from MDNSW and parents letting go, encouraged Dukies to make independent choices. As a result, choice was an outcome of the program and the study findings suggest that the amount of choice experienced had important impact upon the Dukies’ overall experience. Dukies and their parents reported that initially, parents provided the Dukies with the choice of enrolment in the Award. They explained that parents attempted to influence this choice by discussing the benefits of participating in the Award, including access to financial support from MDNSW. Once enrolled in the Award, a number of Dukies described their parents’ concern, leading to incidents where parents attempted to influence their choices of activities because of perceived risks to the Dukies’ health. Parents spoke in detail about the impact of this concern on their ability to be flexible in regards to the Dukies’ choice of activities. For example, one parent tried to convince their child to choose an adventurous journey within closer distance from the family home.

Dukies and their parents reflected on the impact of the Award on the Dukies’ independence. This was presented in the theme: “Got me more independent, doing stuff for myself” (Learning independence). Dukies described learning to become independent as a result of their engagement in the Award. Indeed, the focus of the Duke of Edinburgh’s Award is to empower youth to become independent and have healthy views of themselves and their abilities. Parents felt that Dukies were very reliant on their family prior to their enrolment in the Award.
However, parents reported that the Award taught Dukies to become self-reliant and independent. Dukies were able to learn new skills such as organising, planning and choice making all of which lead to becoming independent (Mithaug, 2005). By learning to become independent, Dukies described their excitement about their future and discussed how they would apply the skills they had learnt from their experience of the Award, to other aspects of their life.

**Self-understanding.**

Self-understanding, according to Kang and colleagues (2014), is when individuals learn more about themselves and develop a sense of self-concept. Through participation and accomplishment of activities, children and young people learn about their strengths and limitations, their values and life expectations (Eriksson & Granlund, 2004). This concept of self-understanding described by Kang and colleagues (2014) was mirrored in this study and reflected in the following themes: “I now know I can do pretty much everything... like everyone else” (Self-belief) and “Thinking bigger and beyond the box... thinking wider and broader” (New outlook and perspective on life).

Dukies and their parents indicated that the Duke of Edinburgh’s Award was a learning process and a road to self-discovery for the Dukies. Dukies and their parents explained that participation in the Award provided them with greater insight about their skills, strengths and limitations and helped them develop a sense of self-concept as a result of their experience. The Dukies indicated that prior to their participation in the Award, they felt limited by their disability. Limiting beliefs about what they could, or could not, do largely influenced their self-concept. To some extent, Dukies said that their disability defined how they viewed themselves and their future. However, Dukies described a shift in their attitudes and self-concept, post completion/participation in the Award and expressed having a more positive outlook on life.
According to Dukies and their parents, the confidence Dukies gained through their accomplishments in the Award led the Dukies to becoming more ambitious in life. Dukies began to seek new opportunities such as employment and independent travel. The Award encouraged Dukies to set bigger goals and not limit their participation due to their physical disability.

**Challenge.**

The concept of *challenge*, a key finding from the current study, is not described in Kang and colleagues’ (2014) model. The concept of challenge has been presented under the dimension of self as it provides a richer understanding of the individual factors that determine optimal participation.

Parents in this study highlighted that initially they encouraged Dukies to enroll in the Award assuming that the program would provide the Dukies with the opportunity to experience challenge. In this study, Dukies and their parents emphasised the importance of engaging in new activities, developing new skills and experiencing challenge. Parents explained that activities were most attractive to the Dukies when there was an element of challenge. When challenge of the activity was low, the Dukies became bored and wanted to give up. In contrast, when challenge was high relative to the Dukies’ skills, for example some of the planning and administration of the Award, the Dukies found this difficult and wanted to give up. Some Dukies explained that they did not enjoy the challenge of the activity while participating in the activity; however in hindsight, they appreciated being challenged and recognised the benefits gained from the experience.

Being a goal-driven program, Dukies worked hard to achieve their goals, which, for many, were novel experiences. When Dukies were able to achieve these goals, they talked about experiencing a sense of achievement and accomplishment, and this was reflected in the theme “I
have achieved goals I set myself” (Sense of accomplishment). As a result of their participation in the Award and experiencing this accomplishment, Dukies discussed becoming more ambitious in life and beginning to seek out new opportunities. Dukies and their parents explained that the skills Dukies gained through their participation in the Duke of Edinburgh’s Award were carried over into areas of participation outside of the Award. For example, once they had completed their adventurous journey and learnt about their capabilities, some Dukies were setting independent travel goals and planning family holidays. Other Dukies who had gained confidence in their communication skills were taking responsibility for arranging their own medical appointments and advocating for their own needs.

According to Kang et al. (2014), optimal participation is a dynamic process that involves continually balancing characteristics of the child, family and environment. Therefore, the child is identified as an active participant continuously seeking participation opportunities that are considered personally meaningful (Kang et al., 2014). Through either personal or environmental adaptations, the child may achieve and maintain this meaningful experience (Hammel et al., 2008; King, 2004). The Duke of Edinburgh’s Award ensured that this balance was maintained throughout the Dukies’s participation in the program. The self-directed nature of the Award, as well as the progression of the program into Bronze, Silver and Gold Awards, are examples of how this balance is maintained. The Dukies participated in activities of their own choices based on their own interests and abilities. This resulted in Dukies selecting activities that matched their skills and abilities.

The findings from this study highlight the importance of a perfect match between challenge of the activity and the individual’s skills. In order to create this “just right” challenge, activities need to be tailored and graded to increase in complexity as the individual’s skills
improve with practice and time. A failure to do this will either result in the individual feeling anxious or bored with the activity.

**Social.**

Social engagement is the child’s involvement in *interpersonal interactions* that take place while the child is taking part in the activity and when he or she is *feeling included (belonging)* (Kang et al., 2014). The theme “*I met someone else with the same disability that understands what it’s like*” *(connection and attitude towards disability)* and “*wanting other kids to have a go*” from the current study reflects the social dimension in Kang and colleagues’ model (2014). In addition, participation in the Award also increased the Dukies social confidence. This was described in the theme “*It helped me communicate with others*” *(Social confidence)*. Therefore, social confidence is an extension of the social dimension of Kang and colleagues’ (2014) model.

Kang and colleagues (2014) contend that a sense of belonging and meaningful participation arises as a result of interactions with others. In the current study, the Dukie made social connections with their peers and individuals in the broader community. Dukies participated in the orientation to the Duke of Edinburgh’s Award gathering as well as the gala evening at which Dukies were presented with their Duke of Edinburgh’s Award completion medals. Both of these events, organised by MDNSW, enabled Dukies to meet other young people who also had a diagnosis of neuromuscular disease. Some Dukies explained that prior to the Award they had no interest in meeting others with a disability; however, their views about this shifted once they had met their peers. Dukies spoke in detail about the value they attached to these relationships and explained that they preferred these relationships more than their able-bodied friendships. Dukies
explained that the common experiences with peers with neuromuscular disease strengthened these relationships.

Dukies in the current study described feeling a sense of belonging to the neuromuscular community as a result of their participation in the Duke of Edinburgh’s Award. Kang et al. (2014) highlight that belonging is one way of gaining meaning through life experiences and may provide motivation and a desire to participate. This element of Kang’s model was reflected in the results of the current study. Dukies described a strong sense of responsibility and desire to contribute to their community - other young people living with neuromuscular disease. Being aware that they were part of a pilot program, Dukies felt responsible for the continuity of the Award in order for their peers with neuromuscular conditions to participate in the future. This sense of altruism may have enhanced the meaning they associated with participation, motivating them to complete the Award as a way of giving back to their community.

Dukies and their parents described the positive impact of the Award on the Dukies’ social confidence. Prior to their participation in the Award, Dukies and their parents mentioned the Dukies’ lack of confidence as a contributing factor to limited social interactions. Some parents discussed the Dukies’ lack of social skills due to this limited social interaction. Furthermore, this lack of social confidence could be a result of continued exposure to society’s negative attitudes towards disability (Chan et al., 2005; Green et al., 2005; Hunt et al., 1996; Imms, 2008a; King et al., 2006; Law et al., 2007; Mihaylov et al., 2004; Shikako-Thomas et al., 2015; Williams & Downing, 1998). Evidence indicates that individuals with disabilities are often faced with negative social attitudes, including stigma and stereotypes, in their day-to-day lives (Barr & Bracchitta, 2015; Louvet, 2007). As a result of these negative attitudes, they may avoid social
interactions, preferring to isolate themselves to their home, thereby resulting in diminished 
quality and quantity of social interactions (Green et al., 2005).

**Determinants of Participation**

Determinants of participation include attributes of the child, family and environment 
(Kang et al., 2014). These three determinants are external to the young person and can influence the outcome of their participatory experience. Table 6 outlines the determinants of participation outlined by Kang and colleagues’ (2014) with comparison to findings from the current study.

**Table 6**


<table>
<thead>
<tr>
<th>Determinant</th>
<th>Description</th>
<th>Examples of participant’s quotes and broader themes from current study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>Age, sex, preferences for particular activities or experiences, physical functioning, cognitive and communication functioning, emotional and behavioural functioning</td>
<td>Dukies to experience life outside of the family home</td>
</tr>
<tr>
<td>Family</td>
<td>Family socioeconomic status, family ecology and functioning, and activity orientation</td>
<td>Access to resources and supports for parents</td>
</tr>
<tr>
<td></td>
<td>Letting go*</td>
<td></td>
</tr>
</tbody>
</table>
Environment
Supportive physical, social, attitudinal and service environments
Opportunity to do new things and learn new skills
Access to resources and support for parents

Note. * Denotes concept not currently described by Kang and colleagues’ model (2014).

Child.

The key child-related attributes include: age, sex, preferences of particular activities or experiences, physical functioning, cognitive functioning and communicative functioning, and emotional and behavioural functioning (Kang et al., 2014). The Dukies in this study all had a diagnosis of neuromuscular disease, which affected their physical functioning. Poor mobility and physical functioning can lead to decreased participation and increased dependence on parents and caregivers. With age and disease progression, this dependence on others may increase; and access to the physical environment increasingly difficult. As a result, participation for these individuals is at times located more within the home with reliance on their family members for activities of daily living (Bushby et al., 2005; Kohler et al., 2009). Parents in the current study praised the Duke of Edinburgh’s Award for facilitating age appropriate experiences for their children. Parents explained how the Duke of Edinburgh’s Award facilitated and encouraged Dukies to participate in activities outside of the family home, experience being away on a holiday without their parents and encouraged them to make their own choices.

Family.

A family’s socioeconomic status, family ecology and functioning, and activity orientation are believed to be key family factors influencing a child’s participation (Kang et al., 2014). In the current study, the socioeconomic element of Kang and colleagues’(2014) model was reflected in
the theme *Access to resources and support for parents*. However, as well as reflecting elements of Kang and colleagues’ (2014) model, this study found an additional important aspect of family in terms of their influence on participation: *letting go*.

Dukies and their parents explained that access to resources and supports for parents through MDNSW, in particular the financial resources, enabled Dukies to take part in their chosen activities, which may not have been possible without this support. This financial support alleviated the potential financial burden on the family. However, parents described the added pressure of needing to motivate the Dukie and help them with the planning and administrative tasks. Parents identified the need for more support from MDNSW with this aspect of the Award.

*“Letting go”.*

In the current study, parents’ letting go appeared to be a key factor that influenced Dukies’ level of participation. Parents spoke about their struggle to let go of their typical caring routines and tasks. For example, not having contact with Dukies when they were away on their adventurous journey was particularly challenging. However, parents praised the Award for encouraging them to let go and were able to recognise the importance of letting go and its impact on the Dukies. Letting go also had a positive effect on the parents, when parents were able to let go; they reported being able to value the time they had to themselves, without their usual care responsibilities. Parents were then able to have much needed respite and spent quality time with other family members.

Parents described their struggles in letting go. Parents described their overwhelming desire to protect the Dukie during their participation in the Award. The relationship between parental anxiety, over-protection and then reduced opportunity for choice and challenge has been well documented (Arellano & Peralta, 2013; Davis & Wehmeyer, 1991; Gardner, 2009). Parents
were cautious about the activities that the Dukies were participating in because of the Dukie’s medical condition and were concerned about potential risks and dangers, especially during the adventurous journey. Parents explained that the adventurous journey was a great source of concern for them as it was such a foreign experience both for the Dukies and their parents. The Award encouraged Dukies to go on their journey without their parents and with limited contact while they were away. Parents explained that this no contact rule was extremely difficult. As a result, some parents tried to influence Dukies’ choices of activity. Dukies discussed how their parents encouraged them to choose the “safest” activities as part of their Award, in particular their adventurous journey. Dukies and parents found a number of strategies that helped them through this process.

The Dukies found the planning process was challenging. However this process helped reassure parents that risks would be minimised and contingency plans were in place in case of an emergency. Further, Parents met formally trained caregivers who would be accompanying Dukies on their adventurous journey. Further, some Dukies also had a short practice journey, which helped with the process of letting go. The Dukies’ successful participation in their chosen activities helped parents to have trust in the Dukies’ abilities and the knowledge that Dukies could cope without their parents. When parents were able to let go, they played a key role in motivating Dukies in their participation during the Award. When Dukies wanted to give up during periods where they were pushed out of their comfort zones, it was the parents who helped to problem solve and supported the Dukies.

**Environment.**

It is believed that factors such as a supportive physical, social, attitudinal and service environments can facilitate optimal participation for children with physical disabilities (Kang et
al., 2014). This was reflected in the following themes: *Opportunity to do new things and learn new skills and access to resources and supports for parents.*

The Duke of Edinburgh’s Award provided the Dukies with a unique chance to participate in activities of their own interest outside of their home and school. Children with neuromuscular disease often live in a society where teachers, parents and other family members have minimal expectations from them (Bray, Bundy, et al., 2010; Sanders, 2006). The young people in this study were enrolled in a worldwide program that is readily accessible to thousands of typically developing young people. This internationally recognised program was for the first time available to a disability group. The Dukies’ experience of the Award mirrors that of typically developing peers, and this highlights the importance of providing young people with disabilities with similar participation opportunities as their healthy peers. Labeling interventions and programs as “disability programs” could downgrade the experience and expectation.

The Award’s structure with embedded resources from MDNSW provided the ideal environment or intervention for the Dukies to achieve optimal experience. The simple and structured program was easy to follow by the Dukies and their parents. Support from MDNSW including practical and financial support alleviated the burden on families and ensured accountability for the Dukies. Dukies met and reported to the coordinator of the Duke of Edinburgh’s Award program at MDNSW. The coordinator was the go-to person for the Dukies and their families. They also facilitated participation and encouraged and motivated Dukies and their parents throughout their Award journey. Furthermore, an assessor who monitored their progress in the activity and a paid caregiver, who provided physical assistance in order for the Dukies to maximise their participation in the Award, also supported Dukies. Both the assessors and the paid caregivers were organised by MDNSW in consultation with the Dukies and their
families. According to parents, access to these valuable resources, in particular the financial support, from MDNSW was a motivating factor for parents to initially encourage Dukies to take part in the Award.

**Improved Quality of Life, Health and Well-being**

Kang and colleagues’ (2014) hypothesized that the experience of optimal participation would result in positive outcomes including a better quality of life, healthier lifestyle, and emotional and psychosocial well-being. This is demonstrated in Table 7.

**Table 7**

*Improved Quality of Life, Health and Well-being: Comparison of Findings with Kang and Colleagues’ (2014) Model*

<table>
<thead>
<tr>
<th>Description</th>
<th>Examples of participant’s quotes and broader themes from current study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuously experiencing optimal participation leads to benefits for quality of life, a healthy lifestyle, and emotional and psychosocial well-being</td>
<td>Dukies</td>
</tr>
<tr>
<td>“I have achieved goals I set myself” (Sense of accomplishment)</td>
<td>“Got me more independent, doing stuff for myself” (Learning independence)</td>
</tr>
<tr>
<td>“It helped me communicate with others” (Social confidence)</td>
<td>“I got to go out into the community” (Increased community participation)</td>
</tr>
<tr>
<td>“I met someone else with the same disability that understands what it’s like” (connection and attitude towards disability)</td>
<td>“I now know I can do pretty much everything… like everyone else” (Self-belief)</td>
</tr>
<tr>
<td>“Thinking bigger and beyond the box… thinking wider and...”</td>
<td></td>
</tr>
</tbody>
</table>
broader” (New outlook/perspective on life)
Improvement in Dukie’s physical health

Parents*
Letting go
“I just did my own thing because I don’t get that very often” (Respite)

Note. * Denotes concept not currently described by Kang and colleagues’ model (2014).

The Duke of Edinburgh’s Award provided an environment in which the Dukies were given choice, an opportunity to experience challenge and the resources required to achieve optimal participation. As a result, this intervention, the Duke of Edinburgh’s Award, resulted in a number of key positive outcomes on the Dukies’ quality of life, physical health, and emotional and psychosocial well-being. In addition to the positive outcomes for the Dukies, parents also experienced a number of benefits as a result of their child’s participation in the Award. These include letting go and having respite.

Dukies.

From Dukie and parent interviews, it appears that the Duke of Edinburgh’s Award program had a major impact on the participation experience of the Dukies both within and beyond the program. Dukies and their parents explained that the Award encouraged Dukies to participate in the community “I got to go out into the community” (increased community participation). Furthermore, Dukies and their parents explained that the Dukies’ participation in the Award encouraged the Dukies to become independent “Got me more independent, doing stuff myself” (learning independence) and learn the skills necessary for adult life such as communication skills and social confidence “It helped me communicate with others (social
The Dukies’ participation in new experiences provided Dukies and their families with insight into the Dukies’ capabilities “Thinking bigger and beyond the box... thinking wider and broader” (new outlook and perspective on life). This led to a shift in the Dukies’ beliefs about themselves and their disability “I now know I can do pretty much everything...like everyone else” (Self-belief). Furthermore, the Award encouraged the Dukies to build connections with peers with neuromuscular disease and people within the broader community and gave them a sense of belonging “I met someone else with the same disability that understands what it’s like (connection and attitudes towards disability). Overall participation in the Award and achieving their goals led to Dukies feeling a sense of achievement and accomplishment “I have achieved goals I set myself” (sense of accomplishment). Some of the Dukies experienced improvements in their physical health as a result of their participation in the fitness component of the Award. These outcomes have surprised all stakeholders. It was initially assumed that participation in the Duke of Edinburgh’s Award would result in Dukies participating in the community and being able to participate in new activities besides just home and school. However, the vast range of outcomes detailed above was not expected by the Dukies, their parents and organisers of the Award at MDNSW. Furthermore, the impact of the Award on the parents and their quality of life were not anticipated.

Parents.

A surprising finding from this study was the positive impact of the Award on the parents. Parents, themselves, were surprised that the program had an impact on them and their relationship with their child. While Dukies were absent participating in their activities, parents described initially struggling to identify what their role was and experienced symptoms of grief, grieving the loss of their role as the caregiver. Some parents described feeling lost and unsure of
ways to fill up their time, losing their appetite, having trouble sleeping, and feeling lonely. Many were consumed with worry about how their child was coping without them. However, they explained that the Award process enabled them to ‘let go’. Letting go was a distinct turning point, and had a profound impact on the Dukies, as mentioned above, and also the parents. Parents began to report a newfound sense of enjoyment that came from having free time. Many of them used this time to reconnect with their personal health and fitness – more exercise, more sleep and to reconnect with their other children. This was reflected in the theme “I just did my own thing because I don’t get that very often” (respite).

**Implications of these Qualitative Findings for Disability Organisations and Health Professionals**

The findings of the present study hold a number of implications for practice. Disability organisations may be able to use lessons from this research to improve the participative experiences of young people living with neuromuscular disease. Disability organisations support, advocate and facilitate participation for people with disabilities and their families. In the current study, the Muscular Dystrophy New South Wales (MDNSW) was the disability organisation that facilitated the participation of the young people with the neuromuscular disease in the Duke of Edinburgh’s Award. The financial resources as well as the practical supports from MDNSW motivated participation in the Award and lessened the burden on the families.

When trying to encourage participation for children with disabilities, disability organisations need to consider the impact of programs on the individual and their families and ensure that adequate supports are in place. When parents feel that they have no control, they increase their level of control as a response to this. Parents reported needing information and support. When parents felt that they had no control or were left out of decisions concerning their
child, they increased their level of control over their child. For example, the no contact rule
during their child’s adventurous journey caused great concern and worry for the parents. A
number of parents suggested that having contact with the caregiver who accompanied their child
would have alleviated some of this anxiety. This highlights the fact that parents need
information, reassurance and to have their feelings respected and validated.

Interviews with the Dukies and their parents brought attention to the timing of
participation opportunities. Some of the participants indicated that they were enrolled in the
Award at the wrong time and that this impacted their overall experience. For example, some of
the participants were in their final year of schooling while others were enrolled at university and
had the pressure of completing their exams and assessments. Medical treatments and surgery can
also interrupt participation and can cause added stress for the parents. This is therefore an
important factor for program developers to take into consideration. A possible solution might be
to increase the level of support for those who might become overwhelmed by the various
commitments in their lives. A few of the participants had decided not to progress to the next
level of the Duke of Edinburgh’s Award due to the competing demands in their lives. It is
therefore important for disability organisations to consult with the young person and their parents
in order to tailor the program to the individual.

It is important for disability organisations to work together with families in order to
support and educate them on ways to motivate and facilitate optimal participation. Parents need
to be encouraged to empower their children to make choices and motivate their child to
overcome obstacles. However, disability organisations can ensure that supports are in place for
parents and their children in order to ensure their longevity.
Limitations of Study

When interpreting these findings, it is important to recognise some limitations associated with the research, which may also provide direction for future work in this area.

Bias

Bias in the context of qualitative research refers to the factors that may influence and impair sampling, data collection, data analysis, and reporting (Drisko, 1997). There are a number of ways in which researchers can limit bias including self-awareness. In this research study, a number of steps were followed in order to minimise bias including:

- Reliability coding- As mentioned above (page 46) one of my associate supervisors, Dr Nicola Hancock and I, each, independently coded the first 2 transcripts prior to meeting together to discuss and ensure coding consistency. Dr Hancock was chosen as one of my associate supervisors for her extensive knowledge and work in the field of qualitative research methodology. Although an occupational therapist and a lecturer at the University of Sydney, she has had no previous experience working with individuals diagnosed with neuromuscular diseases. Hence, she was an unbiased to the population group.

- Reflective supervision sessions- I had regular supervision with my primary supervisor Dr. Paula Bray. Dr. Bray and I met fortnightly and this allowed me the opportunity to reflect on my data collection, process of analysis as well as my emerging findings.

Small study
This study utilised a small sample size. Whilst we did reach data saturation, this was a small study based on one site rollout of a novel opportunity for young people with neuromuscular disease to participate in the Duke of Edinburgh’s Award. There is a need for more studies exploring the experiences of a larger number of individuals with neuromuscular disease participating in the Award in order to find out whether the participants had similar experiences.

**Single time point retrospective data**

The interviews with the Dukies and their parents were conducted after the young person had completed at least their bronze Award. Therefore the interviews were conducted at a single time point and were retrospective accounts, when the Dukies had completed the Award. Interviews were not conducted before they had commenced the Award or while they were participating in the Award. However, there are strengths in retrospection as the time between the completion of the Duke of Edinburgh’s Award and the interview had given the young people and their parents enough time to reflect on the experience. In saying that, there is indeed scope for future research to investigate the participation of these individuals before, and perhaps most importantly, at the exact moment that they were participating in the Duke of Edinburgh’s Award.

**Pleasing the interviewer**

This research was based on semi-structured face-to-face interviews with the participants. The face-to-face interviews are valuable due to the rich responses gained using this method. However, the young people and their parents may not have wanted me, as the interviewer, to know exactly how they felt about the whole experience of the Duke of Edinburgh’s Award. Their responses may have been reframed from what they actually thought to what they thought I might
have wanted to hear. However, as the program expands and the numbers of Dukies increase, the risk of identification will reduce and therefore this issue may resolve.

**Implications for Research**

This study has examined the participation of young people with neuromuscular disease in a community-based program, the Duke of Edinburgh’s Award. The findings of this study have highlighted the positive impact that the Duke of Edinburgh’s Award had on enabling young people with neuromuscular disease to experience optimal participation. In the future, the Duke of Edinburgh’s Award and its impact on the participation of young people with other forms of disabilities could be tested to evaluate its impact on participation of other disability groups.

Furthermore, future research is needed to understand how the rate of change in functioning influences the level of challenge for young people with neuromuscular disease. How is challenge maintained through the adaptive process? The answers to such questions have considerable applied value, demonstrating how challenge plays out in real time at various stages of participation. With such knowledge in hand, program developers are better equipped to maximise the participation experiences across time. Future research into the role of challenge at various time points is needed.

The results of the current study also brought attention on the importance of parents letting go and its impact on their children’s participation. Future research aimed at understanding the complexities of letting go for both parent and child is needed. Developing programs that help parents to effectively let go is crucial. The need for further research into ways parents cope and overcome the initial hardships associated with letting go is a valuable future direction from this study. If managed well, parents can enjoy this time of letting go and have the opportunity for
personal development. Researchers and practitioners alike could do well to examine the process of letting go so that strain is reduced and opportunity is maximised.

**Conclusion**

The aim of this research study was to understand participation for young people living with neuromuscular disease engaging in the Duke of Edinburgh program. Qualitative research methods in the form of semi-structured face-to-face interviews were conducted with Dukies and their parents to get an in-depth understanding of the Dukie’s experience in this novel experience. The findings of the current study highlight the importance of the Duke of Edinburgh’s Award as an ‘intervention’ which appears to be a powerful facilitator of enhanced participation and quality of life for young people with disabilities. The results support the optimal participation model proposed by Kang and colleagues (2014) which emphasises the importance of a supportive environment which supports children with physical disabilities to achieve optimal participation and ultimately an improved quality of life. The importance of choice and challenge as well as supportive parenting, i.e. parents letting go, was reinforced. Results of this study indicate that when these conditions are met, the young people can experience a number of life-changing outcomes including a new and improved outlook on their lives, learning to become independent, improved social confidence and feeling of belonging and connection. For parents, the ability to let go can result in their having the opportunity to have some respite and to focus on their own needs. The results from this study have application for disability support organisations and health care providers wishing to improve the quality of participation for young people with disabilities.


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doi:10.1080/110381201750464520


doi:10.1016/0140-1971(91)90023-k


CHAPTER SEVEN – APPENDICES
Appendix No. 1- Ethical Approval

17 July 2012

Professor Kathryn North
Dean, paediatrics & Child Health
The University of Sydney
Email: kathryn.north@health.nsw.gov.au

Dear Prof North

Thank you for your correspondence dated 9 July 2012 addressing comments made to you by the Human Research Ethics Committee (HREC).

I am pleased to inform you that with the matters now addressed your protocol entitled “Challenge quality of life and participation in people with neuromuscular disease (NMD)” has been approved.

Details of the approval are as follows:

Protocol No.: 15000
Approval Date: 17 July 2012
First Annual Report Due: 31 July 2013
Authorised Personnel: Prof Kathryn North
Dr Paula Bray
Miss Martam Farid
Dr Nicola Hancock

Documents Approved:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version Number</th>
<th>Date</th>
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<tbody>
<tr>
<td>Cover Letter</td>
<td>Version 1</td>
<td>n/a</td>
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<tr>
<td>Opt-in Slip</td>
<td>Version 1</td>
<td>n/a</td>
</tr>
<tr>
<td>Participant Information Statement (Children under 18 years)</td>
<td>Version 1</td>
<td>22.02.2012</td>
</tr>
<tr>
<td>Parental (or Caregiver) Consent Form</td>
<td>Version 1</td>
<td>08.03.2012</td>
</tr>
<tr>
<td>Participant Information Statement</td>
<td>Version 1</td>
<td>23.02.2012</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>Version 1</td>
<td>08.03.2012</td>
</tr>
<tr>
<td>Participant Information Statement (Parent)</td>
<td>Version 1</td>
<td>23.02.2012</td>
</tr>
<tr>
<td>Participant Consent Form (Parent)</td>
<td>Version 1</td>
<td>08.03.2012</td>
</tr>
<tr>
<td>Participant Interview – completed DOE program</td>
<td>Version 1</td>
<td>24.05.2012</td>
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<tr>
<td>Participant Interview – to complete DOE program</td>
<td>Version 1</td>
<td>24.05.2012</td>
</tr>
<tr>
<td>Parents Interview Questionnaire (child completed DOE program)</td>
<td>Version 1</td>
<td>24.05.2012</td>
</tr>
</tbody>
</table>
HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

Special Condition/s of Approval

- Please forward a copy of the safety protocol signed by the student researcher and supervisor, indicating acceptance of the provisions entailed in the document.

Conditions of Approval

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.

- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.

- All serious and unexpected adverse events should be reported to the HREC within 72 hours.

- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

- Any changes to the protocol including changes to research personnel must be approved by the HREC by submitting a Modification Form before the research project can proceed.

Chief Investigator / Supervisor’s responsibilities:

1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.

2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

[Signature]

Dr Margaret Faedo
Manager, Human Ethics
On behalf of the HREC

cc: Mariam Farid
mariam.farid@health.nsw.gov.au

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.
Appendix No. 2 - Letter of Invitation

Dear

Re: Challenge, quality of life and participation in people with neuromuscular disease (NMD)

We would like to invite you to participate in a new research study which aims to investigate the experiences of young people living with neuromuscular disease (NMD), who have/are participating in the Duke of Edinburgh program. Specifically, the study will explore the impact on participation and quality of life. Additionally, the experiences of family members will also be explored.

An information sheet has been included with this letter explaining what is involved in the study. Your participation would be greatly appreciated.

If you would like to participate in this study please do one of the following:

- Use the reply slip provided and tick that you would like to join the study and place it in the reply paid envelope that is enclosed. If you reply Mariam Farid will contact you by telephone to talk to you about the study.
- Contact by telephone (Mariam Farid ph: 02 9845 2620)
- Contact by Fax (Attn: Mariam Farid fax: 02 9845 2633)
- Contact by email (mfarid@uni.sydney.edu.au)

Should you have any questions or require further information please do not hesitate to contact Ms Mariam Farid, Master of Philosophy Student on Phone: (02) 9845 2620, or fax (02) 9845 2633 or email mfarid@uni.sydney.edu.au

Many Thanks

Mariam Farid
Masters Student
University of Sydney

Loretta Downie
Event Manager
Muscular Dystrophy NSW
Challenge, quality of life and participation in people with neuromuscular disease NMD

PARTICIPANT INFORMATION STATEMENT
(CHILDREN UNDER 18 YEARS)

(1) What is the study about?

The goal of this study is to evaluate the Duke of Edinburgh program that has been designed by the Muscular Dystrophy NSW (MDNSW) and the Duke of Edinburgh's Award Australia to find out what you did or did not enjoy about the program so changes can be made in the future to improve the program. More broadly the researchers are interested to know whether the program had any impact on your life in general. Your parents will also be interviewed to find out what they thought about the Duke of Edinburgh program and how we can make it better in the future.

(2) Who is doing the study?

The study is being run by Mariam Farid (Student - Master of Philosophy) and Professor Kathryn North at The University of Sydney.

(3) What do I have to do?

Your task is to take part in an interview with Mariam Farid. You have the choice of coming to the MDNSW office (Meadowbank in Sydney) or have Mariam come to your home and have the interview in your own home. You will then be asked a number of questions about how you found the Duke of Edinburgh program. You will also be asked a few questions about you, your illness and when you were diagnosed. The interview will be audio taped. The plan will be to have one interview but if for any reasons the interview does not finish a second interview will be arranged with you. You will also be contacted before and after the interview/s. Some questions in the interview might make you upset or uncomfortable if this happens you have the choice to stop the interview and withdraw from the research. You will also have access to a Counsellor from MDNSW (02 9809 2111) in case you would like to contact.

(4) How much time will it take?

The interview itself might take about 1 to 1 1/2 hours. You can stop the interview whenever you like. If we are unable to finish the interview another appointment will be made to give you the chance to finish.

(5) Do I have to do the study?

Challenge, quality of life and participation for people with neuromuscular disease NMD
It is your choice to take part or not to take part in the study. If you do decide to take part, you can still choose to pull out if you wish.

You can stop the interview at any time and any information you have given the researchers will not be used in the study.

(6) Will anyone else know?

The researchers may write a report about this study but you will not be named in the report and only the researchers will know your answers.

(7) Do I get anything for being part of the study?

You will not get anything for being part of the study. However your input will help develop the Duke of Edinburgh program further which will benefit the wider Neuromuscular Disease community.

(8) Can I tell other people about the study?

You can tell other people about the study if you wish.

(9) What if I have any questions?

If you have any questions you can contact Mariam Farid on mfarid@uni.sydney.edu.au or (02) 9345 2620 and she will be happy to answer your questions.

(10) What if I am not happy with the study?

If you have any concerns or complaints you can contact The University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

This information sheet is for you to keep.
Appendix No. 4- Adult Participant Information Sheet

Challenge, quality of life and participation in people with neuromuscular disease (NMD)

PARTICIPANT INFORMATION STATEMENT

(1) What is the study about?

You are invited to participate in a study which investigates the experiences of young people living with neuromuscular disease (NMD), who are participating in the modified Duke of Edinburgh program. Specifically, the study will explore the impact on participation and self-perceived quality of life. Additionally, the experiences of family members will also be explored. The three groups (people living with NMD, family members and staff) will be involved in interpreting the findings and translating these into future program developments.

(2) Who is carrying out the study?

The study is being conducted by Mariam Farid and will form the basis for the degree of Master of Philosophy at The University of Sydney under the supervision of Professor Kathryn North Head, Institute for Neuroscience and Muscle Research at Children's Hospital, Westmead.

(3) What does the study involve?

Your task is to participate in an interview with Mariam Farid. You have the choice of coming to the Muscular Dystrophy NSW (MDNSW) office (Meadowbank in Sydney) or have Mariam come to your home and have the interview in your own home. You will then be asked a series of questions about your thoughts on the on the Duke of Edinburgh program. You will also be asked a few questions about you and your child, your child's illness and their experience in taking part in the Duke of Edinburgh program. The interview will be audio taped. The plan will be to have one interview but if for any reasons the interview does not finish, a second interview will be arranged with you. You will also be contacted before and after the interviews. Some questions in the interview might make you upset or uncomfortable, if this occurs you have the choice to terminate the interview and withdraw from the research. You will also have access to a Psychologist from the MDNSW (02 9809 2111) whom you can contact.

(4) How much time will the study take?

The interview itself might take about 1 to 1½ hours. You can stop the interview whenever you like. If we are unable to finish the interview another appointment will be made to give you the chance to finish.

(5) Can I withdraw from the study?

Challenge, quality of life and participation in people with neuromuscular disease (NMD)
Version 1. 23/02/2012
Page 1 of 2
Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The University of Sydney, Muscular Dystrophy Association or The Duke of Edinburgh Award Australia.

(6) Will anyone else know the results?
All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants.

A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

(7) Will the study benefit me?
We cannot and do not guarantee or promise that you will receive any benefits from the study.

(8) Can I tell other people about the study?
You can tell other people about the study if you wish.

(9) What if I require further information about the study or my involvement in it?
When you have read this information, Mariam Farid will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Mariam Farid, Master of Philosophy Student on mfarid@uni.sydney.edu.au or (02) 9345 2620.

(10) What if I have a complaint or any concerns?
Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone), +61 2 8627 8177 (Facsimile) or re.humanethics@sydney.edu.au (Email).

This information sheet is for you to keep.
Appendix No. 5- Child Participant Consent Form

PARENTAL (OR CAREGIVER) CONSENT FORM

I,.................................................[PRINT NAME], agree to permit
...................................................[PRINT CHILD'S NAME], who is aged ......... years,
to participate in the research project

TITLE Challenge, quality of life and participation in people with a neuromuscular disease (NMD)

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved for my child's participation in the project have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Information Statement and have been given the opportunity to discuss the information and my child's involvement in the project with the researcher/s.

3. I understand that being in this study is completely voluntary – I am not under any obligation to consent to my child's participation.

4. I understand that my child's involvement is strictly confidential. I understand that research data gathered from the results of the study may be published however no information about my child nor I will be used in any way that is identifiable.

5. I understand that I can withdraw my child from the study at any time without prejudice to my or my child's relationship with the researcher/s or the University of Sydney, Muscular Dystrophy Association NSW or The Children's Hospital at Westmead now, or in the future.

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6. I understand that the interview can be stopped at any time if my child or I do not wish the interview to continue. The audio recording will be erased and the information provided will not be included in the study.

7. I consent to:
   - Audio-recording YES □ NO □
   - Receiving Feedback YES □ NO □

If you answered YES to the “Receiving Feedback” question, please provide your details i.e. mailing address, email address.

Feedback Option
Address: ________________________________
_____________________________________

Email: __________________________________
_____________________________________

................................................
Signature of Parent/Caregiver

................................................
Please PRINT name

................................................
Date

................................................
Signature of Child

................................................
Please PRINT name

................................................
Date
PARTICIPANT CONSENT FORM

I, [PRINT NAME], give consent to my participation in the research project.

TITLE Challenge, quality of life and participation in people with a neuromuscular disease (NMD)

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, including any inconvenience and discomfort and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

3. I understand that being in this study is completely voluntary – I am not under any obligation to consent.

4. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published however no information about me will be used in any way that is identifiable.

5. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s), the University of Sydney, The Children's Hospital at Westmead or the Muscular Dystrophy Association NSW now or in the future.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to:

- Audio-recording YES ☐ NO ☐
- Receiving Feedback YES ☐ NO ☐

If you answered YES to the “Receiving Feedback” question, please provide your details i.e. mailing address, email address.

Feedback Option

Address: .................................................................

.................................................................

Email: .................................................................

.................................................................

Signature

.................................................................

Please PRINT name

.................................................................

Date

.................................................................
Appendix No. 7- Participant Opt-in Slip

I have read the information letter for the study ‘Challenge, quality of life and participation in people with neuromuscular disease (NMD)’ and would like to discuss this project with Mariam Farid.

Signed:________________________________________

Name:________________________________________

Contact phone number:__________________________

Date:________________________________________

_________Thank you please place in reply paid envelope_________
Appendix No. 8- Young Person Interview Guide

Name: ______________________________________________

Condition: __________________________________________

1. Condition

   • Name
   • Age at time of diagnosis

2. Community Participation

   • What sorts of activities do you like doing at home?
   • Are you involved in any school programs or activities? What?
   • Are you involved in any activities outside of school or home? What?
   • Would you like to be doing more fun social programs or activities outside of school/home?
   • What has stopped you from doing these activities?

3. MDNSW/ Duke of Edinburgh’s Award

   • What are some of the reasons why you wanted to be involved in the Duke of Edinburgh’s Award?
   • When Loretta first spoke to you and asked you to join the Duke of Edinburgh’s Award, what were some of the things you were worried about?
   • Did you consider for any particular reason not to join the Duke of Edinburgh’s Award?
   • What were they?
   • Did you make your own decision to take part in the Duke of Edinburgh’s Award or did someone else influence or encouraged you to?
   • What did you do for your skills part of the Duke of Edinburgh’s Award?
   • Did you like or dislike this?
   • What did you like/dislike about it?
   • What did you do for the fitness/sport part of the Duke of Edinburgh’s Award?
   • Did you like or dislike this?
   • What did you like/dislike about it?
   • What did you do for the volunteering part of the Duke of Edinburgh’s Award?
   • Did you like or dislike this?
• What did you like/dislike about it?
• What did you do for your adventurous journey part of the Duke of Edinburgh’s Award?
• Did you like/ dislike this?
• What did you like or dislike about it?
• If you could pick 2 goals to achieve by doing the Duke of Edinburgh’s Award, what were they?
• Have you achieved them?
• What were your 2 biggest challenges while doing the Duke of Edinburgh’s Award?
• How could MDNSW have helped you to deal with these challenges?
• What do you think needs to change in the Duke of Edinburgh’s Award, to make it better?
• Does your school run the Duke of Edinburgh’s Award for other students in your school?
• Did you ever want to do the Duke of Edinburgh’s Award through school?
• Did anyone ask you to join?
• What stopped you from joining the award through school?
• Do you think the Duke of Edinburgh’s Award was challenging enough, too challenging, not challenging or just right?

4. Independence/ resilience/ Identity

• Did you meet all your goals for the Duke of Edinburgh’s Award?
• How did you feel when you didn’t achieve your goals?
• Did you want to set your goals lower?
• What helped you get back on track when you failed your goals?

• How do you think the Duke of Edinburgh’s Award impacted on your life?
• What have you gained through this experience?
• Were you allowed to take part in social events before doing the Duke of Edinburgh’s Award?
• How did your family support you when you were doing the Duke of Edinburgh’s Award?
• How did your friends support you when you were doing the Duke of Edinburgh’s Award?
• How did your school support you when you were doing the Duke of Edinburgh’s Award?
• How did Loretta (Coordinator of the Duke of Edinburgh’s Award at MDNSW) support you when you were doing the Award?
Appendix No. 9- Parent Interview Guide

Name: ________________________________________________________

Child’s Name: ________________________________________________

Child’s condition: ____________________________________________

Family structure

- Who is in the family?
- Do the parents work? Hours? FT/ PT
- Who is the child’s main carer?
- When was your child diagnosed?
- How would you generally describe your child?
- What sorts of activities do you do as a family?
- How is your child’s condition restricting you as a family from participating in social/ community programs?
- How is your child’s condition restricting them from participating in social/ community programs?

Duke of Edinburgh’s Award / MDNSW

- What were some of your concerns about the program prior to your child commencing?
- What were some of the reason why you wanted your child to be involved in the Duke of Edinburgh’s Award?
- What are your thoughts about the Duke of Edinburgh’s Award?
- Have your views about the Duke of Edinburgh’s Award changed? How?
- How have your attitudes about your child changed now that they have completed the Duke of Edinburgh’s Award?
- What impact has the Duke of Edinburgh’s Award had on your child/ you as a parent/ your family?
- Did you as a parent get anything out of the Duke of Edinburgh’s Award?
- What did you find valuable about the Duke of Edinburgh’s Award?
- Had you heard about the Duke of Edinburgh’s Award before?
- If yes, had you considered enrolling your child?
- If no, what stopped you from enrolling your child into the Duke of Edinburgh’s Award?
- What were you hoping your child could achieve and gain from the Duke of Edinburgh’s Award?
• What changes have you noticed about your child after they completed the Duke of Edinburgh’s Award?
• While your child was away on their adventurous journey what did you do? What did the rest of your family do?
• Was the decision for your child to go away purely their choice?
• What did you think of this aspect of the Duke of Edinburgh’s Award?
• What did you think of the sports/ fitness aspect of the Duke of Edinburgh’s Award?
• What did you think of the Volunteer aspect of the Duke of Edinburgh’s Award?
• What did you think of the skills aspect of the Duke of Edinburgh’s Award?
• Was the Duke of Edinburgh’s Award challenging enough, not challenging, too challenging or just right for your child?
• Should/ Shouldn’t the Duke of Edinburgh’s Award continue in the future? Why?
• Could you recommend some changes in the following areas:
  ➢ Start up/ set up
  ➢ Adventurous journey
  ➢ Volunteering, Skills, fitness/sport sections of the award
  ➢ Communication by MDNSW
  ➢ Finding Assessors

• Have you noticed a change in your child?
• If yes, can you list them?

Do you have any additional comments?