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The Transition to Adulthood for Young Men with Duchenne Muscular Dystrophy: Experiences of Young Adults, Parents, and Service Providers

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Summary

Background: Research into the transition to adulthood for young men with Duchenne Muscular Dystrophy (DMD) remains limited. Existing studies have focused on medical outcomes and the shift from childhood to adult healthcare with little attention given to the lived experiences of these young men as they navigate education, employment, and social participation during the years associated with the transition to adulthood. There is a paucity of international research to date which has explored how young men with DMD experience this transition, or how services support their evolving needs, and none from the Irish context. This study aims to address these critical gaps by providing context-specific, lived experience insights.

Objectives: The research objectives were to explore: 1) how transition to adulthood is experienced by young adults with DMD; 2) parents' experiences of their sons' transition to adulthood; 3) service providers perspectives on current service provision; and 4) existing supports and what might assist young people in preparing for, and during, transition to adulthood.

Methodology: A qualitative descriptive methodology was employed. Participants were recruited using purposive and snowball sampling. Semi-structured interviews were conducted with 8 young men aged 18 and older, 7 parents, and 9 service providers. Tailored interview guides were developed, piloted, and refined for each group. Data were analysed using reflexive thematic analysis (Braun & Clarke, 2022), with each group analysed independently before findings were integrated to inform the overall discussion and conclusions.

Results: Advances in medical care have extended the life expectancy of young men with DMD, reshaping it from a childhood condition to one where individuals are now living longer into adulthood. Participants in this study highlighted that this has not been matched by progress in transition planning, independent living supports, or community-based services, leaving many unprepared for the challenges of adult life. The young men described increasing dependency and limited access to supports such as personal assistance (PA), accessible transportation, and tailored transition planning. They described a growing sense of being left behind as their peers progressed into further

education, employment, and independent living. Parents echoed these experiences, and both young men and their parents spoke of the emotional impact of watching peers move forward into adulthood while their own opportunities for independence remained limited by physical dependence and a lack of targeted support.

Accessibility barriers was a persistent theme. Inaccessible environments in education, public transport, housing, and social spaces restricted opportunities for participation and reinforced dependence on family for mobility, care, and social engagement. Employment was viewed as desirable but largely unattainable due to inaccessible workplaces, limited transportation, and inadequate vocational support. Both young men and parents described being left to navigate education and employment pathways independently, often without formal guidance or structured supports. Social participation, including friendships and romantic relationships, declined after school due to environmental inaccessibility and a lack of inclusive social opportunities. Support and services were described as fragmented, inconsistent, and reactive. Service providers acknowledged service fragmentation and a continued focus on physical health over broader psychosocial and transition planning.

All participants described the contrast between structured, multidisciplinary care provided in children's services and the disjointed nature of adult service provision. Limited access to mental health supports and a lack of structured transition services was described. PA provision, while essential for independence, was under-resourced and difficult to access, with many families reporting challenges in securing reliable, trained support. Overall, the findings identify the need for more holistic, coordinated, and person-centred services that reflect the lived realities of young men with DMD as they navigate adulthood.

Conclusion: This research explored the transition to adulthood for young men with DMD in the Irish context, drawing on the perspectives of young men, parents, and service providers. It highlights the challenges in supporting autonomy and participation as individuals with DMD live longer into adulthood. The study offers valuable insights into how current services respond to their needs and identifies key gaps in support. It calls for DMD-specific, person-centred planning and improved collaboration between supporting services. These findings provide a foundation for the development of more responsive transition supports. Further research is needed to inform the creation of an evidence-informed, co-created transition programme tailored to the needs of young men with DMD.

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1 Introduction

This chapter presents the background and rationale for the study, providing a justification for the selected population and situating the research within an Irish health care context. It offers a brief overview of the methodological approach adopted including the study aims, the methodology and the methods chosen. It concludes with an overview of the thesis.

1.1 Background and Need

Muscular dystrophy (MD) refers to a group of genetically inherited, degenerative muscle disorders characterised by progressive muscle weakness (Birnkrant et al., 2018a). There are several types of MD, such as Duchenne Muscular Dystrophy (DMD), which manifests in early childhood, while others like Limb-Girdle Muscular Dystrophy have a later onset and variable progression (Birnkrant et al., 2018a; Emery, 2002). The most prevalent MD in children is DMD. The incidence of live male births ranges from 1:3500 to 1:5000 (Crisafulli et al., 2020).

DMD is a life-limiting condition, predominantly affecting males due to its X-linked recessive inheritance pattern (Birnkrant et al., 2018a). It is caused by mutations in the dystrophin gene, which result in the absence or deficiency of dystrophin, a protein crucial for muscle stability (Birnkrant et al., 2018a). Without dystrophin, muscle fibres gradually degenerate and are replaced by fibrous and fatty tissues, leading to progressive weakness (Birnkrant et al., 2018a). The onset of symptoms typically occurs between 2 and 5 years of age, with children showing signs of delayed motor milestones, frequent falls, difficulty climbing stairs, and progressive weakness (Birnkrant et al., 2018a). By the age of 10–12 years, most individuals with DMD require a wheelchair for mobility, and as the disease progresses, upper limb function, respiratory, and cardiac muscles also deteriorate (Birnkrant et al., 2018b). Although cognitive function is generally preserved, some individuals, due to changes in dystrophin in the brain, experience learning difficulties, executive dysfunction, and behavioural challenges, which can negatively impact educational and social participation (Ricotti et al., 2016).

Advancements in care and medical interventions (e.g., corticosteroids, cardiac monitoring, ventilatory support) have significantly extended life expectancy for individuals with DMD, with many now living into the third and fourth decade compared to historical expectations of survival into late adolescence (Birnkrant et al., 2018b; Landfeldt et al., 2020). Despite

these advances, DMD remains a life-limiting condition with significant implications for independence and functional skills (Birnkrant et al., 2018a; Landfeldt et al., 2016). Healthcare transition challenges persist, as the transition from children to adult services is often fragmented, characterised by a lack of coordinated care, limited availability of adult neuromuscular specialists, and gaps in multidisciplinary support (Birnkrant et al., 2018c). Social participation is impacted, as young men with DMD encounter barriers to higher education, employment, and social inclusion, which may impact their ability to navigate adulthood independently (Lindsay et al., 2019).

Irish healthcare transition experiences, of adolescents and young adults with long-term conditions in general, as well as the perspectives of parents and healthcare professionals, were explored by Coyne et al. (2019). They found that the transition from children to adult healthcare services was often fragmented, with no national policy standardising this process. The absence of structured transition programmes and gaps in service coordination left many young adults and their families feeling unprepared for the transition (Coyne et al., 2019). This highlighted the need for structured, person-centred programmes to ensure a smoother transfer and maintain multidisciplinary support (Coyne et al., 2019).

For young men with DMD, the transition to adulthood primarily focused on the transfer between clinical services, rather than a broader, holistic approach that encompasses education, employment, and community integration. Given the complexity of DMD, there is a need to examine existing transition supports and explore how young men with DMD can be better supported during this time. This study moves beyond a solely medical perspective that focuses on impairment and clinical management, to adopt a broader occupational approach. It recognises the societal, environmental, and relational barriers that impact autonomy, participation, and independence for individuals with disabilities. The research aims to bridge the medical and functional realities of living with DMD with a deeper understanding of the lived experience—such as service fragmentation and accessibility—that shape young people's experiences of transition to adulthood.

While advancements in medical care have extended life expectancy for young men with DMD, their transition to adulthood is still shaped by social, structural, and systemic factors, including gaps in healthcare, education, employment, and community participation. By centring the lived experiences of people with disabilities, this research explores the transition to adulthood for young men with DMD from their own perspectives while also identifying potential supports to facilitate this transition. While recognising the shift towards identity-first language in disability discourse, this study primarily adopts a person-first

approach, reflecting its foundation within a healthcare context where individual needs and medical care remain central to transition planning.

1.2 Situating the study in an Irish context

There is currently no national database documenting the number of people living with DMD in Ireland. Muscular Dystrophy Ireland (MDI) provided information relating to the number of people with DMD registered with their organisation. MDI is a voluntary organisation that provides support to persons affected by muscular dystrophy and their families through a range of support services. In February 2025 there were 68 boys under 18 years of age and 48 men over 18 years registered with MDI. While this offers an indication of the population, it does not fully reflect the total number of individuals living with DMD across Ireland.

The service landscape for individuals with DMD in Ireland typically involves a mix of specialist hospital-based care, community disability services, and personal and family engagement with advocacy organisations such as MDI. There is no standardised, national approach to transition planning for young men with DMD moving from children to adult healthcare services. As a result, transition experiences vary, with inconsistent access to multidisciplinary teams and social supports. Given the limited Ireland-specific research on DMD transition experiences, this study seeks to provide an in-depth understanding of the lived experience and to support best practice development and inform policy that promotes independence and participation in everyday life.

1.2.1 Positioning of the researcher

I came to this research as a practicing occupational therapist with experience in the Irish healthcare system. My clinical work has included specialist children services for DMD as well as community and school-based services supporting children with physical disabilities. Through this experience, I have observed that transition to adulthood for young people with disabilities has historically received little priority. In both children and adult community teams, the focus has often centred on the transfer of care rather than holistic transition planning that considers how young people will engage in education, employment, and community participation. Throughout my practice, parents and young adults with DMD frequently expressed concerns about this transition, often describing adult services as less structured and responsive than children services. The lack of

coordinated planning and collaboration between services often left many families feeling unprepared.

In recent years, some local services have introduced Young Adult Teams (YATs) to support individuals aged 18–26, reflecting a growing recognition of the need for transition-focused services. However, transition support for young adults with physical disabilities remains limited. A lack of awareness about transition pathways and adult services often leaves young people with complex needs, such as young men with DMD, struggling to maintain independence and participation in adulthood. This study is informed by my direct experience of these challenges. It aims to explore the existing barriers and gaps in transition services and identify supports that can inform best practice in enabling young men with DMD to move into adulthood.

1.3 Aim and Objectives of the Research

This study aims to explore the transition to adulthood for young men with DMD from the perspectives of the individuals themselves, their parents, and service providers, while also identifying potential supports for this transition. To meet the overall aim the following objectives were set:

- To explore how transition to adulthood is experienced by young adults with DMD.
- To explore parents' experience of their sons' transition to adulthood.
- To explore service providers perspective on current service provision for young men with DMD during transition to adulthood.
- To identify existing transition to adulthood supports and explore what might assist young people in preparing for, and during, transition to adulthood.

1.4 Overview of the Study Design

The study employed a qualitative descriptive approach to explore the transition to adulthood for young men with DMD, incorporating the perspectives of the young men themselves, their parents, and service providers. Qualitative description was chosen as it allowed for a rich and detailed account of participants' experiences without requiring extensive theorisation (Sandelowski, 2010). In this study the methodology focused on capturing lived experiences in an accessible manner, ensuring that the voices of participants remained central to the research (Bradshaw et al., 2017). Semi-structured interviews were conducted individually with each participant group, as they allowed for in-

depth exploration of personal experiences while maintaining flexibility in questioning (Braun & Clarke, 2013). Three distinct interview guides were developed and piloted for each group, refining questions to maximise clarity and depth. Purposeful and snowball sampling methods were used for recruitment, ensuring that participants met predefined inclusion criteria. Data was analysed using reflexive thematic analysis, a widely accepted method in qualitative health research for identifying patterns within interview data (Braun & Clarke, 2022). Thematic analysis followed a six-step framework: familiarisation, coding, theme generation, review, definition, and final reporting, ensuring rigor and transparency in data interpretation (Braun & Clarke, 2022).

1.5 Overview of Thesis

In this thesis, Chapter Two provides a review of the current literature relevant to this research study. In Chapter Three, the methodology used for conducting the study is outlined. Chapters Four, Five, and Six present the study's findings, with each chapter dedicated to a specific participant group: young men with DMD, parents, and service providers, respectively. Chapter Seven presents a discussion that synthesises the study's findings in the context of the existing evidence base. It also outlines recommendations for practice, policy, and future research, and examines the study's strengths and limitations.

1.6 Conclusion

The transition to adulthood for young men with DMD remains a critical yet under-researched area in the Irish context. While advances in healthcare have significantly improved life expectancy, the systems that support adulthood are often fragmented. As a result, young men and their families frequently navigate transitions in education, employment, and healthcare with limited guidance. This study aims to address this gap by capturing the lived experiences of young men with DMD, their parents, and service providers, contributing to evidence-based recommendations for enhancing transition supports in Ireland.

2 Literature Review

2.1 Introduction

This research study explores the experiences of young men with Duchenne Muscular Dystrophy (DMD) as they transition into adulthood, incorporating the perspectives of parents and service providers. This chapter first outlines the literature search strategy, followed by a review of literature on how living with DMD impacts individuals across different life stages. It then examines key concepts of emerging adulthood and adulthood milestones, as well as the specific challenges faced by young men with DMD in areas such as education, employment, housing, social participation, romantic relationships, and healthcare transitions.

The literature informing this study spans multiple disciplines, including healthcare, disability studies, sociology, and psychology. While there is a substantial body of research on DMD from a biomedical perspective, less attention has been given to the lived experiences of young men as they navigate the transition to adulthood. Existing research in this area has primarily focused on the transfer from children to adult healthcare services, with most studies conducted in the United States, Canada, the United Kingdom, and parts of Europe, such as Denmark and the Netherlands. However, there remains a significant gap in research examining this transition from an Irish perspective, highlighting the need for further context-specific exploration.

2.2 Literature Search Strategy

A systematic and comprehensive search of the literature was undertaken to identify studies relevant to the transition to adulthood in males with Duchenne Muscular Dystrophy (DMD). To ensure methodological rigor, the search strategy was developed in collaboration with a specialist medical librarian.

The PEO framework—Population, Exposure, and Outcome—was used to structure the literature search. This framework was selected because it is particularly suited to qualitative research questions that aim to explore lived experiences within specific populations (Aveyard, 2019). Given the research focus on understanding the transition to adulthood for young men with DMD, the PEO framework provided a logical and relevant

structure to guide the development of search terms and the selection of sources, as outlined in Table 2-1.

Table 2-1: PEO Framework for Literature Search

Component	Description
Population	Young men with DMD
Exposure	Transition to adulthood, including education, employment, and healthcare transition
Outcome	Current adult roles; participation in adulthood

This framework ensured alignment between the research aims and the search strategy by emphasising the experience of transition and the resulting adult roles, rather than focusing on biomedical outcomes or treatment modalities.

Search terms were developed using keywords and concepts commonly associated with transition to adulthood for men with DMD and those identified in previous studies. Boolean operators and proximity commands (e.g., NEAR/3) were used to refine results. Table 2-2 lists the search terms grouped by theme.

Table 2-2: Literature Review Search Terms

Duchenne Muscular Dystrophy	Transition	Adulthood
'Duchenne muscular dystrophy'	Transition / Transition* / transitioning / transited	'child* to adult*' / 'teen* to adult*'
'duchenne syndrome'	Becoming / becom* / experience / experienced / experiences / negotiate adult/adulthood	adult care / adulthood / NEAR/3 adult Child / childhood / teen teenager/puberty
'duchenne type muscular dystrophy'	Transitional Care Transition to Adult Care	'employment' Employ* / work*

	"Transitional Programs"	School / university / educat*
		opportunit* / participat* / access*

The literature search was initially tested in Embase, Google Scholar and Web of Science Core Collection. A further meeting with the librarian optimised the search for sensitivity, and the search was translated across further databases. See Appendix 1.

The following databases were searched in January 2025:

- ➢ EMBASE
- ➢ Medline
- ➢ CINAHL
- ➢ Web of Science Core Collection
- ➢ Google Scholar

In addition, the ‘Author’ search field was used to identify key contributions within the area of focus, particularly when a closely relevant study by a specific author had already been sourced. To enhance the search further, reference lists from selected articles and textbooks were manually reviewed to identify additional studies and locate primary research where applicable. A targeted search was also conducted to locate Irish literature. All references were imported into EndNote, and duplicates were removed. Titles and abstracts were screened for relevance, and included articles were critically analysed.

Literature from peer-reviewed journal articles and textbook chapters published in English was included. No restrictions were placed on publication year. Both qualitative and quantitative studies were considered to provide a broad perspective on the topic. Studies focusing primarily on genetic research, muscle tissue analysis, or pharmacological interventions related to DMD were excluded. In addition, research relating exclusively to children with DMD who were not within the age range associated with transition to adulthood was omitted, except where the literature explored the medical and functional impact of DMD across the lifespan.

2.3 Understanding DMD

2.3.1 Defining DMD

DMD is a rare and progressive neuromuscular disorder that primarily affects males, caused by mutations in the dystrophin gene (DMD), located on the X chromosome at locus Xp21.2 (Hoffman et al., 1987). In their seminal study, Hoffman et al. (1987) identified dystrophin as the key protein absent in individuals with DMD, confirming its critical role in muscle function and membrane stability. Without dystrophin, muscle fibres become structurally unstable, leading to progressive muscle degeneration, loss of mobility, and eventual respiratory and cardiac complications (Birnkrant et al., 2018b; Emery, 2002). DMD is primarily classified as a neuromuscular disorder, but research has also highlighted its impact on brain function due to the absence of dystrophin in neuronal structures. Neuroimaging and neuropsychological studies have linked dystrophin deficiency to structural abnormalities in the brain, particularly affecting working memory, executive function, and cognitive processing (Doorenweerd, 2020). These deficits can impair language development, attention, and problem-solving abilities, making cognitive and behavioural symptoms a significant, though sometimes overlooked, aspect of DMD (Doorenweerd, 2020). Furthermore, a systematic review by Pascual-Morena et al. (2022) reported higher prevalence rates of autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), depression, anxiety disorders, and obsessive-compulsive disorder (OCD) in individuals with DMD compared to the general population, suggesting broader neurodevelopmental implications of the disorder.

2.3.2 Physical Impact of DMD across life stages

The first symptoms of DMD typically appear between 2 and 10 years of age and may include delayed motor milestones, difficulty climbing stairs, and the hallmark positive Gower's sign, indicating proximal muscle weakness (Birnkrant et al., 2018a). Birnkrant et al. (2018a–c) present a series of three expert consensus clinical guidelines developed by an international panel of specialists to provide standardised, evidence-based recommendations for the diagnosis, management, and care of individuals with DMD. These guidelines serve as a key reference throughout this review. As the disease progresses, motor impairments become more pronounced, with increasing difficulty in running, jumping, and maintaining balance Birnkrant et al. (2018a). A systematic review by Mercuri et al. (2023) highlighted that these early movement difficulties are among the first signs of DMD but are often overlooked, delaying diagnosis and early intervention. Some children also experience cognitive challenges, including delayed speech

development, learning difficulties, and attention deficits, reinforcing the multisystem nature of DMD (Mercuri et al., 2023).

Between the ages of 6 and 12 years, walking and balance become increasingly challenging as progressive muscle weakness advances (Birnkrant et al., 2018b). By the ages of 8 to 10, most individuals with DMD require assistance when climbing stairs, and between the ages of 10 and 12, many transition to wheelchair use for daily mobility (Birnkrant et al., 2018b; Mercuri et al., 2023). Cardiac and respiratory involvement typically begins in early adolescence; however, subtle respiratory decline due to diaphragm weakness may occur at a younger age, even in the absence of clinical symptoms (Birnkrant et al., 2018b). During adolescence (typically between ages 13 and 18), boys with DMD experience significant disease progression, with most becoming wheelchair-dependent due to progressive lower limb weakness and loss of ambulation (Birnkrant et al., 2018b; Mercuri et al., 2023). Scoliosis usually develops between the ages of 10 and 15 due to progressive trunk muscle weakness and prolonged sitting in a wheelchair (Birnkrant, et al., 2018b). As DMD progresses, cardiac and respiratory complications become more prevalent, requiring increased medical intervention (Birnkrant et al., 2018b). Respiratory failure typically results from diaphragm weakness, often necessitating non-invasive ventilation (NIV), such as BiPAP support at night (Birnkrant et al., 2018b).

Bendixen et al. (2014) found that functional limitations in boys with DMD reduce participation in self-care, mobility, and community engagement. Among younger boys, lower strength and slower functional performance were associated with reduced physical activity, while in older boys, these limitations affected both physical and social participation (Bendixen et al., 2014). To support independence and maintain function, enabling equipment such as hoists, powered mobility devices, specialised seating, and adaptive technologies becomes essential in the later stages of DMD (Birnkrant et al., 2018b, 2018c). With advancements in clinical care, including improved cardiac monitoring and non-invasive ventilation, individuals with DMD are now living significantly longer than in previous decades (Birnkrant et al., 2018b, 2018c). Landfeldt et al. (2020) reported that many individuals with DMD now reach early adulthood or beyond, reflecting the growing need for long-term care planning and adult-oriented services.

2.4 Transition to Adulthood

Transition is a dynamic process of change that individuals experience as they move from one life phase to another, requiring adaptation to new roles, identities, and responsibilities (Meleis, 2010; Kralik et al., 2006; Mannino, 2015). It is not limited to a specific timeline but

is shaped by individual experiences, evolving needs, and the broader social context (Meleis, 2010; Mannino, 2015). The transition to adulthood spans multiple life domains, such as healthcare, education**,** employment, and social relationships, and represents a shift from dependence toward greater autonomy and self-determination (Gorter et al., 2011; Arnett, 2000). Arnett's (2007, 2018) theory of Emerging Adulthood frames this phase as one of exploration, instability, and identity development, especially in industrialised societies where traditional milestones like marriage or full-time employment are often delayed. Schwartz (2016) expands on this by highlighting the role of socioeconomic and cultural contexts, noting that access to prolonged self-exploration is not universal; young people from lower-income or non-Western backgrounds may enter adult roles earlier due to external demands and limited resources.

However, the universality of the term Emerging Adulthood has been contested, particularly in relation to individuals with disabilities (Côté & Bynner, 2008; Hendry & Kloep, 2010; Schwartz, 2016). For young men living with DMD, the transition to adulthood is shaped by environmental challenges, fragmented services, and sustained involvement from family, limiting opportunities for autonomy and social participation (Abbott & Carpenter, 2014). While Arnett (2016) explains that adulthood today often follows a more individual and less predictable path for many young people generally, this view does not fully reflect the additional barriers faced by young people with disabilities. Traditional markers of adulthood, such as financial independence, employment, and relationships, often look different for individuals with disabilities, as they often face physical, social, and structural challenges (Lindsay et al., 2019). This can be seen in the experiences of young adults with DMD, who often have less access to education, work, and social activities because of inaccessible environments and their ongoing need for support from family members and professionals (Lindsay et al., 2019).

This has led researchers to advocate for a life course approach to transition, which moves away from rigid milestone-based definitions and instead recognises adulthood as a fluid and contextually shaped experience (Stewart, 2009). Stewart et al. (2014) emphasise the importance of person–environment interactions in shaping the transition experiences of youth with disabilities. This perspective highlights the value of recognising interdependence—where autonomy and support can coexist—and supports holistic planning across domains such as education, employment, community participation, and healthcare (Stewart et al., 2014).

2.4.1 Disability and the Transition to Adulthood

Societal structures, service delivery models, and cultural expectations frequently restrict access to adult roles and autonomy (Bagatell et al., 2017; Stewart, 2014). These factors contribute to reduced opportunities for employment, education, and full participation in adult life (Bagatell et al., 2017). In addition to managing complex medical and functional needs, many encounter structural barriers, such as inaccessible housing and transportation, that further limit their participation in adult life (Stewart et al., 2014).

For young people living with DMD, the transition to adulthood is shaped by fragmented healthcare systems, continued reliance on informal caregiving, and limited opportunities for independent living due to societal and structural barriers (Castro et al., 2025; Lindsay et al., 2016). While medical advancements have extended life expectancy into the third and even fourth decade, transition frameworks and services have struggled to keep pace with these evolving needs (Castro et al., 2025; Landfeldt et al., 2020). Historically, the prognosis of early mortality contributed to underdeveloped adult services and transition policies, leaving gaps in care continuity (Abbott et al., 2012; Hoskin, 2020; Lindsay et al., 2019).

A growing body of research has called for a shift from emphasising "independence" to embracing "interdependence" as the foundation for transition planning for young people with disabilities (Hoskin, 2020; Stewart et al., 2014). This perspective reframes autonomy as being achieved not in isolation but through relational and systemic support (Stewart, 2014). Comparative work by Hoskin (2020) further illustrates this; young men with DMD in Denmark, supported by well-established personal assistance programmes, report higher levels of perceived autonomy than their English counterparts, who face more fragmented care systems. This view, echoed by Stewart et al. (2014), affirms that autonomy is not compromised by assistance but strengthened when individuals are supported in exercising choice and participation.

HIQA (2019) describes autonomy as an individual’s capacity to make informed decisions about their care and daily life, guided by their own values and preferences. Social inclusion initiatives such as peer mentorship, advocacy training, and disability rights education further operationalise interdependence by fostering both autonomy and a sense of community belonging. Transition services grounded in this framework may be better positioned to support young adults with disabilities in pursuing meaningful adult roles without the unrealistic expectation of full self-sufficiency (Abbott & Carpenter, 2014; Hoskin, 2020; Stewart, 2014;). Although DMD-specific research remains limited, existing studies identify barriers for young men during the transition to adulthood. Lindsay et al.

(2019) highlighted restricted opportunities for employment, education, and community engagement among young adults with neuromuscular conditions, including DMD. Similarly, Hoskin (2020) draws attention to fragmented services and limited institutional support, which result in continued reliance on caregivers. These findings reflect broader concerns around the lack of tailored transition planning for young people with DMD, underscoring the need for further empirical research focused on this population.

2.5 Transition Challenges for Young Men with DMD

For young men living with DMD, the transition to adulthood is shaped by the challenges of managing progressive physical decline, navigating ongoing reliance on caregiving, and addressing gaps in support systems across areas of daily life and participation (Barak et al., 2025). Although autonomy is commonly associated with independent living, for young men with DMD it often means balancing a desire for self-direction with the need for support in everyday tasks such as personal hygiene, mobility, and medical care (Barak et al., 2025; Lindsay et al., 2019). Research highlights that many young men with DMD continue to rely on family members, particularly parents, for personal care during the transition to adulthood, largely due to limited access to personal assistance programmes and increasing physical dependency (Hoskin, 2020; Lindsay et al., 2016). In a recent study conducted in Israel, Barak et al. (2025) found that 58% of young adults with Duchenne or Becker muscular dystrophy required significant support with activities of daily living. In the absence of adequate personal assistance programmes and external caregiving networks, many remain in the family home into adulthood (Donaldson et al., 2021; Lindsay et al., 2016).

While research on broader disability populations such as studies on young people with cerebral palsy (CP) has shown that high self-care dependency is linked to remaining in the family home well into adulthood (Reddihough et al., 2013; Rozkalne et al., 2019), DMD-specific research, examining how young men personally experience this transition, remains limited. Few studies explore how young men with DMD balance progressive dependency with aspirations for autonomy during the transition to adulthood. Little attention has been given to how young men with DMD exercise decision-making autonomy in the context of personal care—such as directing parents or personal assistants—and how this shapes their broader sense of independence and engagement in adult roles.

In addition to caregiving and self-care challenges, external structural barriers further limit opportunities for independence and participation during the transition to adulthood (Lindsay et al., 2019; Stewart et al., 2014). Lindsay et al. (2019) provide one of the more

focused contributions, identifying how inaccessible public environments, societal expectations, and transport limitations restrict young adults with DMD and other neuromuscular disorders from fully engaging in meaningful occupations such as work, education, and leisure. Their findings demonstrate how structural barriers, including inadequate transport services and inaccessible buildings, exacerbate social isolation and limit engagement in adult roles (Lindsay et al., 2019).

Broader disability studies, such as those by Stewart et al. (2014) and Lindsay et al. (2024), echo many of these challenges in populations with physical disabilities more generally. Stewart et al. (2014) highlights how environmental barriers such as inaccessible transport systems and housing shortages compound the challenges faced by young people with disabilities as they transition into adulthood, limiting opportunities for employment, education, and independent living. Lindsay et al. (2024) further highlight how inadequate housing and infrastructural access, combined with poor service coordination, perpetuate dependence on family caregivers and reduce participation in adult roles.

Both studies emphasise that young people with disabilities often face a mismatch between their individual needs and the environments they navigate, particularly when formal supports are fragmented or insufficient (Lindsay et al., 2019; Stewart et al., 2014). However, there remains a lack of research specifically examining how environmental barriers impact the transition to adulthood for young men with DMD.

2.5.1 Education and Employment Barriers

The transition to adulthood for young men with DMD is often shaped by barriers to accessing education and employment, limiting opportunities for financial independence and participation in adult life (Donaldson et al., 2021; Lindsay et al., 2016). Many encounter inaccessible educational environments, limited vocational support, and inadequate accommodations during their transition from school to further education or training (Lindsay et al., 2016). The physical demands of work, transportation limitations, and the need for personal assistance during the workday further restrict access to sustainable employment (Lindsay et al., 2019). Barak et al. (2025) found that these challenges remain a major concern for young adults with DMD, who frequently report a lack of targeted transition support in both education and employment. Similarly, Castro et al. (2025) emphasise that fragmented transition frameworks often fail to support young men with DMD in engaging in education or employment, reinforcing prolonged dependence on family caregiving.

These DMD-specific findings are consistent with broader disability research, including studies on CP populations. Research studies have reported that young people with physical impairments encounter systemic service gaps, physical inaccessibility in educational institutions, and limited access to employment supports (Björquist et al., 2015; Reddihough et al., 2013; Magill-Evans et al., 2005;). In addition, a systematic review by Lindsay et al. (2018) highlighted that adolescents with disabilities frequently encounter poor coordination between child and adult services, limited awareness of available supports, and significant barriers in accessing inclusive vocational and post-secondary education pathways. Research has shown that systemic failures often leave young people with disabilities underprepared for independent adult roles, including meaningful participation in education and employment (Björquist et al., 2015; Freeman et al., 2018; Lindsay et al., 2019).

There is limited empirical research on how young men with DMD navigate the employment landscape or engage meaningfully in post-secondary education and vocational training (Barak et al., 2025; Castro et al., 2025). Despite increasing recognition of the challenges they face in these domains, few studies explore how young men with DMD personally experience and manage these transitions to adulthood (Barak et al., 2025; Donaldson et al., 2021). Existing research tends to focus on descriptive outcomes, such as low employment rates and underrepresentation in higher education, without providing deeper qualitative insight into how young men with DMD manage these barriers or what strategies they employ to pursue autonomy and participation in adult roles (Barak et al., 2025; Donaldson et al., 2021). Furthermore, there is limited evidence on how young men with DMD experience the intersection between education, employment, and other transition domains, such as caregiving dynamics, personal assistance use, or welfare system navigation (Castro et al., 2025; Lindsay et al., 2019). This highlights the need for DMD-specific studies that explore how systemic barriers, personal aspirations, and external supports shape educational and employment outcomes during adulthood. Addressing this research gap is essential to inform the development of tailored transition frameworks, vocational programmes, and higher education supports that reflect the unique needs and aspirations of young men living with DMD.

2.5.2 Housing and Financial Barriers

Young men with DMD often encounter considerable challenges in securing accessible housing and achieving financial stability during the transition to adulthood. Many report unmet needs in supported accommodation and employment, which contribute to

prolonged dependence on family caregiving and limited opportunities for independent living (Barak et al., 2025; Donaldson et al., 2021). As a result, remaining in the family home is common, often due to a lack of wheelchair-accessible housing and systemic barriers within welfare and housing systems (Hoskin, 2020; Lindsay et al., 2016). Hoskin (2020) highlights how policy differences influence these outcomes; in Denmark, publicly funded personal assistance and housing adaptations support greater independence, whereas in England, limited financial and service support delays the transition out of the family home.

Although DMD-specific research on housing and financial barriers is limited, studies involving broader disability populations, offer valuable insights. These studies consistently report systemic service gaps, shortages of accessible housing, and low employment rates as contributing factors to extended reliance on family caregivers well into adulthood (Björquist et al., 2015; Reddihough et al., 2013; Magill-Evans et al., 2005). Inadequate coordination between children and adult services, as well as limited information about available housing or welfare supports, further hinder young people's preparation for independent living (Björquist et al., 2016; Freeman et al., 2018).

Despite increasing recognition of these challenges, there remains a notable gap in DMD-specific research that examines how young men navigate decisions related to housing, financial security, and independent living. Few studies explore how financial insecurity shapes access to personal assistance, housing adaptations, or broader transition planning (Barak et al., 2025; Castro et al., 2025). Additionally, little is known about how young men with DMD experience the intersection of housing, caregiving dynamics, and welfare system navigation during this critical period (Donaldson et al., 2021; Lindsay et al., 2019). Addressing these gaps is essential to informing inclusive and responsive transition frameworks that reflect the diverse needs, aspirations, and lived experiences of young men with DMD. Such evidence is vital for the development of effective policy and service models that enable greater autonomy and promote successful transitions into adulthood.

2.5.3 Social Participation and Romantic Relationships

The transition to adulthood for young men with DMD is often shaped by challenges in maintaining social participation, peer relationships, and emotional connection (Donaldson et al., 2021; Ee et al., 2024; Lindsay et al., 2019). Feelings of social isolation and disconnection from peers are commonly reported, with Ee et al. (2024) identifying physical impairments, reliance on family caregivers, and reduced independence as contributing factors. Limited mobility, environmental inaccessibility, and a lack of inclusive social opportunities frequently result in restricted engagement in both structured and informal

social settings (Donaldson et al., 2021; Lindsay et al., 2019). Lindsay et al. (2019) found that individuals with DMD encounter persistent barriers to participating in everyday occupations such as school, employment, and recreation that are often essential for forming and sustaining peer relationships. These findings align with broader disability research, which emphasises how cultural expectations and inaccessible environments can limit opportunities for developing friendships and engaging in community life (Stewart et al., 2014).

As young men with DMD move into adulthood, aspirations for autonomy often include building and maintaining meaningful peer relationships, including but not limited to romantic partnerships (Hoskin, 2020). Hoskin (2020) notes that the young men frequently express a strong desire for inclusion and closeness whether through friendships, shared experiences, or intimate relationships, but often face a lack of structured opportunities and tailored support to pursue these goals. Ee et al. (2024) similarly found that although interest in peer engagement is high, young men with DMD often lack opportunities to participate in peer activities or develop close social bonds. Moreover, psychosocial needs, including emotional intimacy, friendship, and identity exploration, are rarely addressed in clinical or transition planning contexts, where physical health and self-care are often the priority (Earle & Blackburn, 2020; Hoskin et al., 2024).

The need for physical assistance with daily tasks can also impact privacy and independence, which may complicate efforts to establish and maintain relationship boundaries (Earle & Blackburn, 2020). Young men with DMD often navigate the tension between seeking closeness with others and needing caregiver support, which may be ever-present in social situations (Hoskin et al., 2024). In response to these barriers, many turn to digital platforms such as gaming communities, online forums, and disability advocacy groups as alternative spaces for social participation, connection, and identity exploration (Hoskin et al., 2024). While these platforms offer valuable opportunities for social connection, there is limited research on their specific role in fostering sustained friendships or psychosocial wellbeing in young people with DMD. Despite these findings, most transition programmes continue to prioritise medical and self-care goals while overlooking relational and psychosocial aspects of adulthood (Earle & Blackburn, 2020; Hoskin et al., 2024). There is a clear need for more holistic and inclusive approaches to transition planning support that address friendship, social participation, and emotional connection not just independence in daily living. Supporting young men with DMD in building and maintaining social networks is critical to promoting a sense of belonging, identity development, and overall wellbeing in adulthood.

2.5.4 Healthcare Transitions

Healthcare transition is frequently conceptualised as the transfer from children to adult services; however, research consistently emphasises that this shift should be continuous, developmentally appropriate, and tailored to the individual's needs to prevent poor health outcomes and disengagement from services (Blum et al., 1993; Crowley et al., 2011). The transition from children to adult healthcare services represents a challenge for young men with DMD as they move into adulthood (Castro et al., 2025; Lindsay et al., 2016). Transition frameworks for this group often fall short of these goals, as healthcare systems have not evolved to address the complex, long-term needs of this population (Lindsay et al., 2016). Many report difficulties accessing specialised adult neuromuscular services and navigating fragmented care pathways (Lindsay et al., 2016).

There is a shift from highly coordinated, family-centred children services to adult systems that emphasise self-management and individual responsibility (van Staa et al., 2011). Lindsay et al. (2016) found that young men with DMD often feel unprepared and unsupported during the move to adult healthcare, largely due to the loss of familiar children's teams and insufficient transition planning. Communication gaps between children and adult providers further exacerbates these challenges, often leaving families responsible for managing records, scheduling appointments, and coordinating complex care plans (Castro et al., 2025; van Staa et al., 2011). Similar findings are reflected in broader disability research; for instance, Stewart (2009) highlights how parents of young people with physical disabilities often feel overwhelmed when navigating disjointed adult healthcare systems.

Despite growing awareness of these challenges, significant gaps remain in both research and clinical practice. While consensus guidelines advocate for early, coordinated, and person-centred transition planning in neuromuscular disorders (Castro et al., 2025), few studies explore how young men with DMD personally experience the transition from children to adult services. Most existing literature focuses on systemic barriers, such as service fragmentation and limited access to specialised care (Lindsay et al., 2016), yet little is known about the impact on young men with DMD. In the Irish context, Coyne et al. (2019) report that young people with long-term conditions frequently experience poor continuity of care and inadequate service coordination during healthcare transitions. However, these findings may not fully reflect the unique experiences of individuals with progressive conditions like DMD, whose care needs evolve significantly over time. Furthermore, there is a lack of qualitative research examining how young men with DMD adapt to increased self-management demands, or how they perceive autonomy and health responsibility in the adult care setting. These gaps point to the need for more responsive

and holistic transition frameworks that address the unique challenges associated with DMD during the move to adult healthcare settings.

2.6 Gaps in Research and Rationale for the Present Study

While research on DMD and the transition to adulthood is growing, it has primarily focused on healthcare transitions and medical outcomes (e.g., Lindsay et al., 2016; Castro et al., 2025). Few studies provide a holistic understanding of the transition process, particularly from the perspectives of young people with DMD, their families, and service providers. The purpose of this review was to explore the existing literature on the transition to adulthood for young men with DMD and to better understand how this transition is experienced by individuals themselves, their parents, and professionals involved in their care.

Only a limited number of relevant studies were identified. Advances in multidisciplinary care have significantly improved survival, with many young men with DMD now living into their 30s and 40s (Landfeldt et al., 2020). Yet, these young men continue to face substantial challenges during the transition to adulthood, including fragmented healthcare systems, limited access to specialised adult services, and inadequate psychosocial and emotional support (Castro et al., 2025). Gaps in care and unmet psychological needs are commonly reported. As a result, the gap between available transition supports and the complex, evolving demands of life with DMD has become increasingly evident.

Notably, no research was found that explores how young men with DMD and their families navigate the transition to adulthood within the specific context of the Irish healthcare and social care systems. Similarly, there is a lack of research examining how service providers perceive and support this life stage. This study aims to address these gaps by contributing to a richer understanding of the lived experiences of young men with DMD in Ireland. It also aims to generate insights that can inform future practice and policy development relating to transition services.

2.7 Conclusion

This chapter has examined the current literature on DMD and the transition to adulthood. Chapter Three will outline the methodology and methods of the study.

3 Methodology

3.1 Introduction

This chapter provides the methodology for the study. It outlines the qualitative research approach chosen and details the methods used. This includes sampling strategies, data collection and analysis methods, and an evaluation of measures taken to enhance research quality. Additionally, ethical considerations, as well as the strengths and limitations of the research design, are outlined.

3.2 Research Aims

This study aims to explore the transition to adulthood for young men with DMD from the perspectives of the individuals themselves, their parents, and service providers, while also identifying potential supports for this transition. To meet the overall aim the following objectives were set:

- To explore how transition to adulthood is experienced by young adults with DMD.
- To explore parents' experience of their sons' transition to adulthood.
- To explore service providers perspectives on current service provision for young men with DMD during the transition to adulthood.
- To identify existing transition to adulthood supports and explore what might assist young people in preparing for, and during, transition to adulthood.

3.3 Qualitative Methodology

Qualitative research is a methodological approach which aims to understand human experiences through rich descriptive data rather than numerical analysis (Bradshaw et al., 2017). It allows researchers to explore phenomena in their natural contexts, emphasising subjective interpretations and lived experiences (Bradshaw et al., 2017). To explore experiences of transition to adulthood for young men with DMD and to identify potential supports for this transition a qualitative descriptive approach (Sandelowski, 2010) was selected.

According to Sullivan-Bolyai et al. (2005), the goal of qualitative descriptive research is to use simple, understandable language to provide a thorough and accurate representation of experiences, making it a suitable choice in relation to the research aims of capturing the

young men's experiences. To ensure that the experiences of all participants, i.e. the young men, their parents and service providers, are adequately reflected, qualitative description focusses on investigating and understanding a phenomenon, in this instance DMD, a process such as transition to adulthood, or the viewpoints of those involved in the study such as the perspectives of the participants (Bradshaw et al., 2017). A qualitative descriptive design is distinct from other qualitative techniques such as grounded theory, ethnography, and phenomenology since it does not require extensive theorisation or recontextualisation, instead concentrating on the lived experience of the transition to adulthood for young men (Neergaard et al., 2009).

Qualitative description is centred on providing a clear and detailed account of an experience in accessible language (Doody & Bailey, 2016; Sullivan-Bolyai et al., 2005). Throughout the process, the researcher remains close to the data, ensuring that participants' perspectives and experiences are accurately portrayed in their own words (Sandelowski, 2000; Sullivan-Bolyai et al., 2005). According to Bradshaw et al. (2017), a qualitative descriptive approach is especially useful in health research, as it allows for the rich description of complex health issues such as DMD, and helps researchers gather direct accounts from participants. It seeks to provide a rich description of an experience or event. Throughout the research process the researcher aims to remain close to the "surface of the data and events" (Sandelowski, 2000, p. 336), where the participants' perspective is used to describe the experience (Sullivan-Bolyai et al., 2005).

There are limitations to the qualitative descriptive approach. It is acknowledged the researcher's perspectives and biases will have an influence on what is selected and described within the findings (Sandelowski, 2000). In the case of this research the researcher herself has experience of working within DMD clinics and has knowledge of existing services within the context of the Irish healthcare system. To acknowledge and consider this, reflexive notes were maintained by the researcher throughout each stage of the research process. Additionally, because qualitative descriptive research is not theory-driven, it does not contribute to the development of new theories or conceptual frameworks and may be considered to have less theoretical depth and conceptual rigor (Sandelowski, 2000). However, as this study was concerned with lived experience and perceptions of participants this was not considered necessary.

3.4 Ethical Considerations

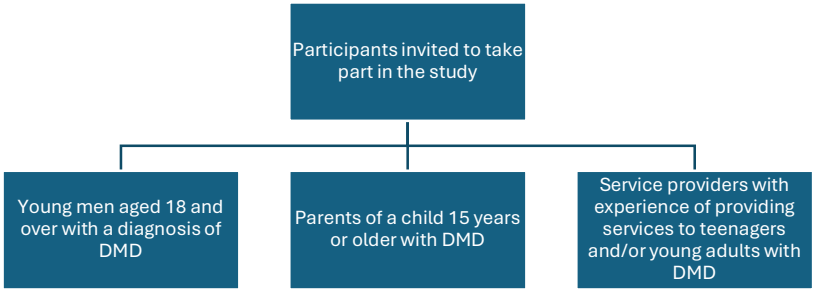
Ethical approval for the involvement of the young men was granted on December 2nd, 2022, and amended in June 2023 to include all persons 18 and over. This was granted as part of a larger study titled 'Supporting Transitions to Adulthood Resources (STAR) Project', currently being conducted by the supervisor examining the transition to adulthood for young adults with physical and sensory impairments. Ethical approval was obtained through Trinity College Dublin's Faculty of Health Sciences Ethics Committee. (Reference number: 220612) (Appendix 2). Ethical approval for the inclusion of parents and service providers was obtained through Trinity College Dublin's School of Medicine Research Ethics Committee on the 31st of January 2024, (reference number: 2916) (Appendix 3). A Data Protection Impact Assessment (DPIA) was reviewed and approved by the Data Protection Officer (DPO) at Trinity College Dublin (DPIA record of review Appendix 4) on the 14th of March 2024.

The study followed the Trinity College Dublin data management policies relating to data processing and storage. The researcher transcribed the interviews, which were completed both in-person and online via Zoom. All interviews were audio recorded only, video recording was not used in-person or online. Safeguards to protect participant identity and ensure secure data management were implemented, including anonymising all data and utilising password-protected documents stored on encrypted devices. Each transcript was assigned a participant number, and original audio files were deleted once transcription was completed. Participation was entirely voluntary, and informed consent was obtained through signed forms, ensuring that participants fully understood and agreed to the terms of the research.

3.5 Study population

The study involved three separate participant groups. See Figure 3-1.

Figure 3-1: Study Participants



Participants were selected based on their ability to offer meaningful, relevant, and insightful perspectives on the lived experiences of transitioning to adulthood for young men with DMD. Young men who had recently or were currently experiencing the transition to adulthood were centralised. Parents of children aged 15 and older, including adults, were included not to triangulate the young men's experiences, but to provide insight into parents' perceptions of their transition to adulthood. Rather than seeking an objective truth, this study aimed to explore different perspectives on the experience (Braun & Clarke, 2024). A service provider for the purpose of this study refers to a healthcare professional, such as a physiotherapist, occupational therapist, nurse, social worker, or psychologist, as well as support workers involved in services that facilitate the care and management of individuals with DMD. The study sought participants who worked with teenagers or young adults with DMD. Services providers offer valuable insight into current service delivery, highlighting systemic challenges, resource limitations and practical issues impacting transition to adulthood. Their practical knowledge about multidisciplinary teamwork, and service integration provides a foundation for recommending targeted supports that could enhance service delivery for men with DMD during transition to adulthood.

3.5.1 Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were applied to determine eligibility for participation, ensuring alignment with the study's objectives. These criteria were essential for enhancing the reliability of the findings, maintaining the study's relevance, and addressing ethical considerations effectively. See table 3-1.

Table 3-1: Participant Inclusion and Exclusion Criteria

	Men Diagnosed with DMD	**Parents**	**Service Providers**
Inclusion Criteria	Young men aged 18 and over with a diagnosis of DMD.	Parents of a child, 15 years or older with DMD. Have sufficient spoken English to participate in an interview without a translator.	Service providers who have experience of providing services to teenagers and/or young adults with DMD.
Exclusion Criteria	Men not diagnosed with DMD. Men who do not have sufficient English proficiency to participate in a semi-structured interview.	Those who are not parents to a child diagnosed with DMD. Parents who do not have a son with DMD, who is aged 15 years or older. Parents who do not have sufficient English proficiency to participate in a semi-structured interview.	Service providers who do not have experience of providing services to teenagers and/or young adults with DMD

Previous studies on the transition to adulthood for individuals with DMD have included both adolescents and young adults. In this study, young men aged 18 and over were included, as they could provide informed consent and because the transition to adult services in Ireland typically occurs between the ages of 16 and the early 20s, often determined by age or the completion of secondary education (Coyne et al., 2019). Parents of children aged 15 years and older were included to explore caregiving experiences during the transition to adulthood. Similar participant criteria have been used in previous studies investigating the parental role in transition to adulthood (Stewart et al., 2014; Lindsay et al., 2016; Barak et al., 2025). Service providers working with both children and adults with DMD were also recruited to ensure broad representation of service perspectives. Research on transition for individuals with DMD frequently cites the American Academy of Pediatrics (2002), which emphasises that transition planning is a

gradual process rather than a single event. It is recommended that this process begin around the ages of 13 or 14 (Barak et al., 2025; Birnkrant et al., 2018). Accordingly, the study sought professionals who worked with teenagers or young adults with DMD.

3.6 Data Collection

Qualitative data were collected using semi-structured interviews. This method is particularly effective for exploring participants' lived experiences, aligning with the study's qualitative research objectives (Braun & Clarke, 2013). Focus groups were considered, however, due to the different locations of the participants and their availability for participation, semi-structured interviews were considered the most appropriate method for exploring the research objectives in this study. According to Bradshaw et al. (2017), semi-structured interviews are an integral part of the qualitative descriptive approach and are particularly suitable for data collection in healthcare research. To maximise accessibility and accommodate participants' preferences, interviews were offered in both face-to-face and virtual (Zoom) formats. This approach supported participation from individuals regardless of their location or mobility challenges and recognised potential barriers to in-person interviews. A more detailed discussion and justification of the interview process and mode of delivery is provided in Section 3.6.3.

Open-ended questions were used. The benefits of using open-ended questions in healthcare studies include their ability to elicit rich, detailed responses, which enhance the depth of understanding of the lived experiences of the participants (Braun & Clarke, 2013). The flexibility enables the researcher to explore and gain insights that structured questions may overlook (Holloway, 2005). Questions can be adapted in real time based on participants' responses acknowledging that individual experiences of living with DMD, parenting a child with DMD during the transition to adulthood and providing services to this population (Creswell & Poth, 2018). Because open-ended questions don't impose any restrictions on participants' responses, they reduce researcher bias (Sandelowski, 2000). Furthermore, they enabled the researcher to be responsive, to build rapport and encourage conversation on topics that could be perceived to be personal and sensitive considering the DMD diagnosis. Open ended questions can present challenges for the researcher due to the generation of large amounts of data that requires time to organise and interpret (Creswell & Poth, 2018)

3.6.1 Data Collection Tool: Interview Guide

Separate interview guides were developed for the young men, parents, and service providers.

3.6.1.1 Development of Interview Guide for Young Men with DMD

The development of the interview guide began with generating questions aligned with the research objectives and relevant literature. These questions were refined through regular discussions between the researcher and the research supervisor. To assess the guide's effectiveness, a pilot interview was conducted between an adult gentleman living with Becker's Muscular Dystrophy and the researcher. While he was not eligible for the study, due to not meeting the inclusion criteria of having a DMD diagnosis, he shared similar medical and functional challenges to individuals with DMD, making his insights valuable.

The interview guide was structured into three sections. Part 1 encouraged discussion about the young men's current lives, their experiences of leaving school, and transitioning to college if this was the case. Part 2 focused on friendships, personal relationships, and social connectedness. Part 3 explored how DMD influences adulthood, the supports currently available, and what participants perceived as helpful in facilitating a transition into adulthood.

Feedback from the pilot interview was positive. The participant found the questions comprehensive in capturing the transition experience and noted that the interview had a good flow. However, he suggested refining the structure of the questions to encourage more open-ended responses. For example, instead of phrasing questions in a way that might lead to simple "yes" or "no" answers, he recommended asking, "How do you feel or think about…?" Additionally, he advised that questions should allow participants to provide general insights rather than requiring direct personal responses. For instance, rather than asking directly about their own romantic relationships, a broader question such as, "Thinking about personal or romantic relationships, can you describe what this might be like for a young person with DMD? Do you have any examples of relationships you know about that you can share?" would be more effective. (See Appendix 5 for the full interview guide.)

3.6.1.2 Development of Interview Guide for Parents

The interview guide for parents was initially developed by formulating questions based on the study's research objectives and informed by relevant literature. These questions were

subsequently refined through ongoing discussions between the researcher and the research supervisor. To evaluate the clarity and relevance of the guide, a pilot interview was conducted by the researcher and supervisor with a mother and her young adult son living with DMD. While they did not participate in the final study, their insights contributed to the refinement process. The decision to include both mother and son in this pilot interview was intentional. It allowed the researcher to observe how parents narrate their experiences in the presence of their child, and whether this dynamic would influence the openness or detail of their responses. This helped inform the decision to interview parents and young men separately during the main study, ensuring that both groups could speak freely and without influence from the other.

The parent interview guide was structured into three sections. Part 1 focused on the parents' perspectives on their son's current life, their concerns, and the supports available for the transition to adulthood, both generally and in relation to healthcare. Part 2 explored the impact of this transition period on both the parent and their son, how they were supported, and how DMD influenced decisions and expectations for the future. Part 3 encouraged parental reflection, asking whether their concerns for this transition period had been realised, whether they had additional concerns for the future, and how they perceived their role in supporting their adult son's life. Parents were also invited to suggest services or supports that could facilitate the transition to adulthood.

After the interview, the researcher and research supervisor reflected on the interview process. While the interviewees did not suggest any changes to the existing questions, the experience highlighted the importance of interviewing parents and young men separately to allow for more open and uninfluenced responses. The interview guide was further refined to incorporate additional prompts within questions, ensuring a smoother flow and encouraging more detailed responses. For example, the question "What were the teenage years like for you and your child?" was rephrased to provide more structure and prompts: "During the teenage years, were you involved with different services? Were hospital visits a large part of your life? How was your child's health during those years?" While still open-ended, this revised question provided parents with clearer starting points to share their experiences. (See Appendix 6 for the final interview guide.)

3.6.1.3 Development of Interview Guide for service providers

The interview guide was developed by first creating questions that reflected the study's objectives and were informed by pertinent literature. These questions were then revised and improved through continuous collaboration between the researcher and their

supervisor. To ensure relevance and clarity, a copy of the research questions was shared with a service provider working with individuals with DMD for feedback. Additionally, the researcher and research supervisor met with representatives from Muscular Dystrophy Ireland (MDI), including the Head of Services and the Research Officer, to gather input on the questionnaire design and service provision considerations.

The interview guide was structured into three sections. Part 1 focused on the service provider's role and experiences related to the transition to adulthood for individuals with DMD, including current services and supports available. Part 2 explored general resources and supports outside of current service provision. Part 3 examined how transition support could be improved in the future.

Feedback from the consultation highlighted the need for greater clarity and conciseness in some questions. However, no additional areas of questioning were suggested. Based on this feedback, the researcher and research supervisor collaborated to refine certain questions. For example, the question "Is there an opportunity to address how young people can manage their emotions throughout the transition journey?" was revised to "Is there an opportunity to address how young people can manage their emotions and talk to their peers and others about DMD throughout the transition journey?" This revision aimed to make the question clearer and more specific for participants. Final adjustments were made, and the revised interview guide was agreed upon. (See Appendix 7 for the final version.)

3.6.2 Recruitment and sample size

Once ethical approval was obtained through Trinity College Dublin's School of Medicine Research Ethics Committee, both purposeful and snowball sampling was used to recruit participants. Gatekeepers, including Muscular Dystrophy Ireland (MDI) and the Central Remedial Clinic (CRC) were utilised to disseminate information to any potential participants. The information flyer, study invitation, participant information leaflet and consent form (See Appendix 8,9,10,11) were sent via email to a nominated person in each organisation to share with potential participants.

All available platforms were utilised by MDI to share this information. It was included in their newsletter and the flyer was posted, by their communications officer, on their social media platforms. Within the CRC information was also shared with all teams including the managers of the CRC community-based children's teams.

Anyone interested in participating in the study contacted the researcher directly via email for further information. Interest in participating was indicated by returning a signed consent form (See Appendix 11) attached to the study information. The participant and researcher then arranged a suitable time and date for the interview to take place.

Recruitment proved to be slow across all groups. The researcher worked closely with the gatekeepers and upon invitation both the researcher and research supervisor attended an MDI information day for families living with DMD. The researcher presented information to the parents relating to the background and aims of the study and expressed an interest in hearing from any willing participants. Both the researchers and supervisor were available to discuss the research with parents, young men and service providers present on the day. A presentation was also given to service providers within the CRC, again highlighting the background and aims of the study and expressing an interest in hearing from any willing participants.

Repeated dissemination of the study flyer and information was undertaken by the communication officer in MDI. Upon invitation from MDI and approval from the clinic consultant, the researcher attended national adult DMD clinics with their clinic liaison officer to share information leaflets and flyers with parents and young men attending the clinic.

The participant information pack invited recipients to share the study information with other potential participants to facilitate snowball sampling. Twenty-four participants across the three participant groups were recruited:

- 8 young men aged 18 and over with a diagnosis of DMD.
- 7 parents of a child 16 years or older with DMD
- 9 service providers with experience of providing services to teenagers and/or young adults with DMD

3.6.3 Interview Process

Semi-structured interviews were conducted between December 2023 and June 2024. Any person meeting the inclusion criteria who expressed interest in participating was included at any point in the data collection period. That is participants in each of the three groups were being interviewed at the same time. Each participant had the opportunity to choose between a face-to-face interview or an online interview via Zoom. Online interviews provided convenience, flexibility, and greater accessibility, allowing individuals to

participate who might otherwise have been unable to attend an in-person interview due to location or time constraints (Archibald et al., 2019; Lobe et al., 2020). The researcher travelled to any participant who indicated a preference for an in-person interview, however, online was also offered to accommodate participants. Archibald et al., (2019) also described challenges in establishing rapport and the possible occurrence of technical disruptions as limitations in conducting online interviews. To mitigate these issues, strategies such as using video instead of audio-only calls and ensuring stable internet connections were implemented to create a smoother and more comfortable experience for participants (Archibald et al., 2019). All interviews were audio recorded, with the participant's consent.

The time range for length of interview ranged from 50 minutes to 137minutes. See table 3-2

Table 3-2: Length of the Interview in minutes.

	Young men		Parent		Service provider
P1	98 minutes	P9	76 minutes	P16	43 minutes
P2	42 minutes	P10	108 minutes	P17	64 minutes
P3	70 minutes	P11	119 minutes	P18	47 minutes
P4	56 minutes	P12	80 minutes	P19	61 minutes
P5	88 minutes	P13	71 minutes	P20	75 minutes
P6	53 minutes	P14	137 minutes	P21	53 minutes
P7	40 minutes	P15	96 minutes	P22	67minutes
P8	53 minutes			P23	103 minutes
				P24	110 minutes

3.7 Data Analysis

A qualitative descriptive approach was used in this research to create accounts of participants' experiences and perspectives of transition to adulthood for young men with DMD. As part of a qualitative descriptive approach, data from the interviews of the participants must be compiled into themes and subthemes (Vaismoradi et al. 2013). To

achieve this, reflexive thematic analysis (Braun & Clarke, 2022) was used. Thematic analysis is effective for small-scale in-depth interviews where patterns across participants are explored (Nowell et al., 2017). It is widely used in healthcare research to explore individuals' experiences (Braun & Clarke, 2019). It allows for a structured yet interpretative approach, making it useful for capturing both explicit and latent meanings in the data (Nowell et al., 2017).

Following the guidelines outlined by Braun and Clarke (2022), the researcher and research supervisor adhered to a systematic series of steps throughout the analysis process. Transcripts for each group were analysed independently. The six-step framework (familiarisation, coding, theme generation, review, definition, and reporting) ensures rigor and reproducibility (Braun and Clarke, 2022). These steps were repeated for each of the three participant groups to ensure consistency and thoroughness.

They included:

(1) *Becoming familiar with the data:* This involved listening to the audio recordings of the interviews, completing transcriptions for each interview, and reading the transcripts several times. Preliminary notes were taken, and summaries were generated for each interview. Regular discussions and reviews with the research supervisor helped optimise familiarisation with the data.

(2) *Generating initial codes:* The initial coding process involved identifying distinct raw data segments from the transcripts to extract potentially meaningful and relevant information. Exploratory comments, both descriptive and conceptual, were generated and recorded as memos alongside the raw data segments.

The researcher and research supervisor independently coded the first two transcripts from both the young adult interviews and the service provider interviews. Through line-by-line coding, separate sets of initial codes were developed. For the parent transcripts, the researcher completed this step independently.

A coding document was created in Microsoft Word for each group, and these documents were later compared and discussed. Throughout this process, the original transcripts were referenced to ensure the codes accurately represented the interview data. Through joint discussion, the codes were modified, generating an agreed initial coding system which was transferred to NVivo (version 12.23.2 https://lumivero.com/products/nvivo/). As coding progressed for the remaining transcripts new codes were added within NVivo.

The researcher used a systematic and rigorous coding methodology where codes evolved, collapsed, and split as the analysis continued under the guidance of the research supervisor. This coding system was used to manage the data and code the interviews as three separate groups.

(3) *Generating initial themes*: The researcher transferred the finalised codes from NVivo to Microsoft Word for further analysis. Clusters of related codes were examined and interpreted to identify common patterns of meaning (Braun and Clarke, 2022). Initial themes were generated by analysing the dataset in relation to the research objectives. Regular discussions between the researcher and research supervisor contributed to the development of the initial themes.

(4) *Reviewing themes:* Initial themes were collapsed and split through consensus between the researcher and supervisor and thematic maps were created using Microsoft Word.

(5) *Defining and naming themes*: Through an ongoing process involving several discussions with the research supervisor, the researcher created summaries of each developing theme. This led to agreement on the finalised generated themes.

(6) *Writing up:* The final step involved writing a cohesive narrative that addressed the research objectives through the integration of coded data into analytical thematic accounts. The findings for each participant group were written and presented separately, with each theme supported with illustrative quotations. The researcher and supervisor collaborated throughout the writing process. Insights from each group were integrated for the final discussion to provide a comprehensive understanding of the experiences and perspectives of the three groups.

3.8 Rigour in Qualitative research

Credibility in qualitative descriptive research is established through transparency, reflexivity, and deep engagement with data (Nowell et al., 2017). According to Braun and Clarke (2022), credibility is also established through an awareness of researcher subjectivity. Credibility is reinforced when the analytical process is logically structured and well-justified (Tracy, 2010).

3.8.1 Transparency

Clear documentation of the analytical process, including how themes are generated, refined, and reported, strengthens credibility (Nowell et al., 2017). Within this chapter there is documentation relating to how the researcher and research supervisor worked

collaboratively to analyse and report the findings from the semi-structured interviews completed with all participants. Through various discussions and ongoing reflection, the themes relating to the research objectives were generated and presented in the findings. Rather than simply categorising data, reflexive thematic analysis encourages researchers to construct rich, meaningful themes that accurately reflect participant experiences (Braun & Clarke, 2022).

3.8.2 Reflexivity

Reflexivity is central to this approach, emphasising the researcher's role in knowledge production (Braun & Clarke, 2019). Keeping a reflexive journal allows researchers to critically examine their assumptions and biases throughout the research process (Finlay, 2006). The researcher maintained a reflective journal and inputted entries immediately following each interview. This enabled the researchers' initial impressions to be captured.

There was also opportunity for both the researcher and supervisor to meet and discuss initial impressions and thoughts following each interview. This process was particularly valuable, as coming from a clinical background presented challenges in stepping back and actively listening to participants rather than identifying needs and offering solutions, as would typically be done in a clinical setting. Reflecting on underlying assumptions regarding all three participant groups proved beneficial. Participants shared deeply personal stories, and the ability to build strong rapport contributed to a smooth and effective interview process. However, having a debrief with the research supervisor afterward was especially helpful, providing space to process the emotional impact of these narratives, particularly those shared by parents and young men. This reflection enhanced awareness of the researcher's position, which was essential when proceeding with the analysis and coding of transcripts. Reflection and collaboration with the research supervisor throughout the analysis process played a crucial role in highlighting and providing space to consider the researcher's positioning and underlying beliefs in relation to the generation of themes and, ultimately, the findings of the research.

3.8.3 Engagement with the data

Prolonged engagement with the data and repeated reading of transcripts allows for a deeper, more nuanced understanding of the findings (Nowell et al., 2017). The transcripts were recorded and transcribed by the researcher which provided opportunity to become closely familiar with the data. The recordings of the participants voice helped the

researcher create an auditory memory for each transcript. This helped form a connection with the written text and as analysis progressed, the researcher could identify small pieces of text and associate them with the participant's voice. This created a connection for the researcher with the participants enabling deeper understanding and helping to keep meaning and participants experiences alive throughout the process.

As themes are constructed through interpretation rather than direct extraction of data member-checking is not essential however, ensuring that findings align with participant perspectives remains essential (Braun & Clarke, 2019). The use of personal quotes and text from the interviews helps to share the participants voice within the findings and increases transparency as readers can hear what was said within the context of the study.

3.9 Participant Summaries

The demographic profiles of the three participant groups are presented in Tables 3-3, 3-4, 3-5.

Table 3-3: Information relating to the young men recruited for the study

NO.	Location of Interview	Age	Parent participated in the study	Current home situation	College		Work experience	Currently working
					Past	Now		
1.	Online	22	Yes	Lives at home Rural setting	yes	no	yes	no
2.	In-person in his home	21	No	Lives at home Rural setting	yes	no	no	no
3.	In-person in his home	31	No	Lives at home Urban setting	no	no	no	no
4.	Online	20	No	Lives at home Rural setting	yes	no	no	no
5.	Online	22	No	Lives at home Rural Setting	yes	yes	yes	Yes Fulltime
6.	In-person in his home	22	Yes	Lives at home Urban Setting	yes	yes	no	no
7	Online	20	Yes	Lives at home Rural Setting	yes	no	yes	Yes Parttime

8	In-person in his home	19	Yes	Lives at home Rural Setting	yes	yes	yes	no

Table 3-4: Information relating to the parents recruited for the study

NO.	Location of Interview	Age of son	Son participated in the study	Parent working	Supporting son with Activities of Daily Living
1.	Online	19	Yes	No	Yes
2.	Online	19	Yes	Yes	Yes
3.	Online	16	No	No	Yes
4.	Online	20	Yes	No	Yes
5.	Online	20	Yes	No	Yes
6.	Online	19,21	No	Yes	Yes
7.	In-person in their home	20	Yes	Yes	Yes

Table 3-5: Information relating to the service providers recruited for the study

NO.	Location of interview	Clinical Role	Clinical Experience relating to DMD	Age group service provider has experience working with
1.	Online	Senior Occupational Therapist	Children's disability Community Team	Up to age 18
2.	Online	Senior Occupational Therapist	Community Adult services	Age 18 upwards
3.	Online	Senior Occupational Therapist	Specialist disability service clinic	Up to age 18
4.	Online	Senior Occupational Therapist	Specialist DMD Clinic	Up to age 18
5.	Online	Clinic Liaison Officer	Liaison person at all DMD medical clinics	DMD all ages -childhood and adult
6.	Online	Senior Physiotherapist	Specialist disability services	DMD all ages -childhood and adult

7.	Online	Senior Occupational Therapist	Children's disability Community Team & Specialist DMD clinic	Up to age 18
8	Online	Senior Clinical Neuropsychologist	Specialist DMD children's medical clinic	Up to age 18
9	Online	Senior Occupational Therapist	Children's disability Community Team & Community Adult services	DMD all ages -childhood and adult

3.10 Limitations within the methodology

The qualitative design of the study, paired with the use of thematic analysis, which depends on the researcher's interpretations to identify themes and assign meaning to the data, introduces the potential for bias or subjectivity. To reduce this risk, both the researcher and the research supervisor collaborated on data coding and analysis, employing cross-checking procedures at every stage of the analytical process.

The sample size for each group was relatively small due to recruitment challenges; however, in line with Braun and Clarke's (2016) argument that qualitative sample size should be guided by data richness rather than rigid numerical thresholds, this sample size is considered sufficient for both the methodology and the method (Braun & Clarke, 2024).

Twenty-four participants were recruited across the three groups. DMD is a rare, life-limiting condition with a limited population of young men, parents, and service providers available for participation. Qualitative data collection does not set out to be generalisable and is thus representative of the perceptions and experiences of the participants. The services providers were predominantly occupational therapists and only one support worker was recruited although multiple attempts were made to increase this number. This is a limitation of the study.

Member checking, which is often viewed as a strategy to enhance the credibility of qualitative findings, was not undertaken in this study. While participants were offered the opportunity to review their individual transcripts, and these were provided upon request, no further steps were taken to verify the thematic interpretations with participants. Although this decision was influenced by the time constraints of a Master's research project and the specific methodological approach adopted, the inclusion of participant feedback on the findings could have offered an additional layer of insight. While the absence of member checking does not invalidate the findings, its inclusion might have contributed to a richer

understanding of the data by allowing participants to respond to the researcher's interpretations.

3.11 Conclusion

This chapter had provided an overview of the methodology, and the research methods used to explore the lived experiences of young men with DMD, their parents, and service providers during the transition to adulthood. It details the research design, methodology, data collection, and analysis procedures, highlighting the rigorous measures taken to ensure credibility, while acknowledging limitations within the chosen methodology.

The results of the analysis are presented in the next three chapters. Chapter Four will present the findings from the perspectives of the young men who participated in the study. Chapter Five will explore parents' experience of their sons' transition to adulthood. While Chapter Six will examine service providers perspective on current service provision for young men with DMD during the transition to adulthood.

4 Findings: The transition to adulthood experiences of young men with Duchenne Muscular Dystrophy

This chapter presents the findings from the analysis of the interviews with the young men. There were seven themes generated. These are presented in Table 4-1

Table 4-1: DMD Interview Themes

Themes
1. Current lives and the transition to adulthood 2. Leaving school behind 3. Employment and education paths 4. Social and romantic connections 5. Accessibility is the main barrier for Transition to Adulthood - Physical access - Transport access - PA and HCA access 6. Transition to adult healthcare services 7. Skills to support transition

4.1 Current lives and the transition to adulthood

The eight men who participated in the study were aged 19 to 31 years. They described their late teens and twenties as a time of ongoing changes in their physical and medical conditions. Living with DMD was characterised as challenging and deteriorating, with one participant stating, *'it doesn't ever get better it only gets worse as you get older'* (P3). Over half of the young men described this stage of life as "*scary*", highlighting the uncertainty and unpredictability of how the condition might progress.

The transition into adulthood brought feelings of uncertainty for many participants. One young man reflected on this, saying:

> ‘*I was just thinking I'm grown up now and, you know, what's my life gonna be like?’(P1).*

highlighting the emotional toll of living with a progressive condition. Another participant expressed how the uncertainty surrounding his future weighed heavily on his mental well-being:

> *‘Mentally, it affects you the most. Just because you're scared a lot of the time—you have a diagnosis, but you don’t know how it will progress. You don’t know where your health will be in a few years, and you don’t know how much of a future you will have. So, yeah, huge mental problems, lack of security.’ (P5)*

Despite this over half of the participants described the importance of maintaining a positive outlook on life. One participant reflected on the necessity of embracing life saying, *‘Enjoy life as much as you can for as long as you can’* (P5). Another focused on living well and adapting to his circumstances. *‘You just have to keep going,’* he explained, *‘People always say doom and gloom about these things, but you have to live as well, and that’s very important’* (P1).

All the participants highlighted an increasing reliance on others for activities of daily living (ADLs), describing a growing need for assistance with tasks such as eating, drinking, and toileting. Many required full-time personal care, which heightened their frustration over the loss of independence. One young man shared his feelings, stating ‘*I can't do as much anymore. It's kind of frustrating’* (P3).

Another participant described how he depended on his father for daily assistance with toilet transfers, allowing him to attend university, stating, *‘My dad's basically acting as the HCA for me now’ (P6).* This dependence on family was perceived as a barrier to independence, with another young man reflecting, *‘Maybe I feel like even more of a kid than when I was 15 or 16 now because I need more care’ (P5).*

This change in physical ability and functional skills meant that many men avoided going out alone, because of challenges environments were now placing on them, due to their changing physical skills:

> *‘Usually, I go over there with my dad or something… because I’m not able to use my card to pay the barber. So, like I kind of need the help with all those things anyway*.’(P6)

All the men were living in the family home at the time of the study. Three described an interest in investigating living independently. One participant shared his long-term plan:

'Like, I'd love to be able to eventually move out and stuff like that, and that's my plan anyway. I'd love to be there, but it takes a while, you know.' (P1)

Others expressed similar aspirations stating:

'My plan is to move out and get my own place. Live with friends from school in town.'(P5)

They considered that living independently should be achievable with the right supports in place as one young man explained:

'You should be able to move out, you should be able to get the supports in place. You should be able to control your own life and not just have to rely on your parents all the time.'(P1)

4.2 Leaving School Behind

Leaving school brought about changes in structure and routine to the daily lives of the young men. Many expressed missing '*the old routine'* and feeling '*disappointed to leave'* (P6) their school years behind. Concerns about losing touch with friends was prevalent, as one participant shared, '*I had finally made four or five friends and thought I'm probably not going to get to see them as much now'* (P5). This transition often triggered feelings of sadness, loneliness, and anxiety about the future. One participant described life after school as particularly isolating:

'it's quite lonely after leaving. I'd gone from being around friends and just people I knew very well. It all just sort of stops. And it… was quite hard for me to get over the fact that it was over, just it all ended.' (P3)

These fears made it difficult to enjoy life and manage emotions, contributing to feelings of loneliness. Life transitions such as leaving school can bring this to the fore and lead to comparisons with the experiences of others:

"I was probably depressed really about the whole leaving school. Just not being able to go forward with how you usually do when you leave school. And as well as that just the loneliness, just sort of everyone else, they have moved on.' (P3)

As they transitioned out of school, all participants expressed feeling they had fewer opportunities compared to their peers, particularly when it came to typical life experiences such as socialising, traveling, or attending events. Their reliance on support from parents or PAs further contributed to these challenges:

'Like everything is set up here for me, so I'm just stuck here, where everybody else sort of has that freedom and choice to leave, which can be very tough.' (P1)

One participant highlighted how the growing awareness of these differences can impact the mental health of young men living with DMD:

'I'd say it probably affects your mental health the most. I think you're in your head all the time. Because you see everyone around you having these different opportunities and experiences that you just can't have. And maybe it's tougher around that age because you just notice more differences between yourself and everyone else.' (P5)

This sense of limited access to opportunities often led to feelings of being left behind. One young man described experiencing '*just the loneliness, just sort of everyone else, they have moved on' (P6).* Additionally, participants highlighted the lack of freedom and flexibility compared to their peers as a significant struggle. The need for extensive planning and dependence on support systems restricted spontaneity in both daily activities and social interactions:

'Because you're trying to keep up with people, but all they wanted to do is just party and drink. So yeah, it can be tough… Like even during my internship, a lot of the interns would go out afterward, and I wasn't really able to do that. I had to go home.' (P1)

For many young men, having a clear understanding of available options and opportunities during the transition from secondary school to adulthood was crucial. One participant highlighted the difficulty of this transition, stating:

'People often forget about the transition from secondary school to third-level education, it can be very hard as well.' (P1)

Some young men identified a lack of tailored preparation and support as challenging when they were preparing to leave school**.** Guidance on opportunities for further education was available**,** with career guidance teachers helping identify suitable courses. Some teachers also acknowledged the needs of students with physical disabilities and recommended accessible colleges. While the advice was helpful, most felt that the support provided did not adequately address their specific needs. As P1 described:

'it's nice to go to somebody and say, here, this might be good for you because it's not as physical, it's not as practical, you can do this, you can do that. I would say for maybe someone with Duchenne that they got told about how much they can participate in a course, I think it'd be really good.' (P1)

Ongoing reliance on self-research or family support to source information on courses, accessibility options, and funding was described as overwhelming by one participant who stated:

> *'Even if you search online, you get thousands of articles… no one's ever in one place.'*(P1)

He also suggested specifically tailored DMD support and information to assist when choosing colleges and courses would be advantageous. He felt an access programme or route to college, specifically tailored to the needs of students living with DMD, would be valuable:

> *'I think programmes need to be developed, such as being able to access information…..even if you don't want the information, I think you should be told about it…..I think that's very important, being able to know about our PA services, being able to know about certain grants and stuff that colleges do, just be able to live your life and not be afraid.' (P1)*

Most young men who participated would like if information relating to available grants, resources, supports and what opportunities that were available to them were more easily accessible:

> *'Just have them resources available to you, also to know about travel grants, such as getting a taxi to and from college……like a good web page…. instead of having to go see somebody about it. No-one's ever in one place…. if you search online, you get like 1000s of articles you know.' (P1)*

4.3 Employment and Education Paths

Regarding further education, all except one had participated in a course after leaving school, such as post leaving certificate courses, and university courses. Most just considered it the next step after school as explained by one participant:

> *'It's what everyone was doing so I said I'd just give it a try.'(P4)*

However, their experiences of college varied. One participant enjoyed the social aspect:

> '*It was so great getting to just see people and get to be with people, especially because my class was very small. I was like 10 or 12 people. And so yeah, that's really nice.'(P1)*

In contrast, another participant admitted he '*didn't really make new friends'* in college (P5).

Aside from friendships, DMD influenced college experiences in various ways. Fatigue was a challenge, as one participant explained:

> *'I: What impact do you think Duchenne has on your experience of being in college?*
>
> *P: Tired, tired.*
>
> *I: Being tired.*
>
> *P: Well, I'm not tired too often, but tiredness would be if you did like loads of things in the one week you'd be exhausted.' (P8)*

While another shared how a lack of awareness about his condition created challenges:

> *'in college not many of them knew what I had and what my needs were and stuff like that. They didn't know that I didn't have to do like physical activity and stuff like that.*'(P4)

He found it challenging to complete the physical aspects of the course and explained:

> *'There was a lot of outside kind of stuff, like measuring and stuff, and that was kind what I found difficult…. we went to X one time to do kind of measuring of buildings and stuff, I didn't go, so it would probably have been too much for me.*' (P4)

At the time of participation in the study three were enrolled in a course and another two participants were investigating further educational opportunities.

Regarding employment, two participants were employed—one full-time and another part-time. Another had recently finished with a role and was investigating future employment opportunities. For other participants employment was not something they viewed as an option due to the challenges involved. One participant admitted:

> *'It never really appealed to me because it just would have been so stressful. I just never really thought about it… there was never really something I wanted to do.' (P3).*

Finding suitable work was difficult, as many jobs required physical tasks that weren't feasible. One participant shared:

> *'I remember with me, it was like, the post office—you could do some work in the post office. But no, that won't work because I'd have to lift heavy boxes, and that's definitely not going to work.' (P1).*

Another expressed frustration:

> *'I'd rather be doing hands-on stuff, like maybe construction, but I'm not able, so I have to come up with something else.' (P4).*

Beyond job suitability, there were logistical challenges also. Long commutes were exhausting, where one participant described having to '*travel two hours in, two hours home every day'* which left him *'wrecked' (P1),* with another participant sharing that the physical demands of full-time work, 'f*ive days a week'* was *'too much'* for him*. (P5)*. Workplace accessibility was also a concern. One participant explained:

> *'A lot of doors weren't easy to push. The toilets weren't really as good as maybe they should be. I'm lucky with where I am, but for some other people, I can see where challenges come in.' (P1)*

4.4 Social and romantic connections

Almost all the young men commented on wanting to fit in within their peer group. One participant described how he was '*the only one in my social group in school that had a physical disability*' and he found this '*quite isolating'* and how this was something he could never '*talk about*.' (P3) Another described how '*you feel like a bit of an outcast with Duchenne*.' (P1) Many participants also described how they really wanted to fit in yet maintain their identity as a person living with DMD:

> *'I just want to fit in, just want to be like everybody else. So, I think it's, that'll be really hard for people with disabilities. It's to not lose their identity of having a disability. Trying to just fit in and mould with everybody else.' (P1)*

One of the young men described how '*a night out isn't always the easiest in a wheelchair*.' It can be difficult '*to be comfortable in yourself.'(P5)*

Many participants highlighted the challenges of forming new connections and integrating into social groups after leaving school due to the rarity of DMD and the challenge of explaining the condition to others. This often led to discomfort and anxiety in social settings. One participant noted, '*young people... are quite awkward around disabled people'* (P3), while another highlighted the difficulty of conveying the full impact of DMD, stating, '*It's quite hard to get across just how debilitating it is*'(P3). Another young man struggled with how much to disclose about the condition as he didn't want '*the person to get scared off or anything*.' (P1)

Online communication was seen by all as a valuable tool for building social networks and forming relationships with people who share similar interests. One participant described how it supported him to '*meet people with the same interests'* and enabled him to '*make friends with people, like all different people'* (P2). However, in-person social opportunities, particularly in college settings, were often limited. Many participants felt disconnected due

to the structure of their schedules and their reliance on support. One participant shared how the demands of his routines left little room for social engagement:

> *'most days … my lectures are like right after each other so I'm kind of going from one to the next and I don't really have much time to hang around because … once my lectures are done I just head home'. (P6)*

Opportunities for interaction, such as group projects, were valued but rare. One participant explained:

> *'I've been talking to like a few of them once or twice, but that's kind of about it'(P6).*

One young man chose not to attend college after witnessing his older brother, who also has DMD, struggle to build connections. He felt that the college environment was not designed to support the inclusion of students with physical disabilities:

> *'a lot of the time he was sort of left and like, just all social experience of colleges isn't very well set up for disabled people.' (P3)*

Experiencing mental health challenges further compounded these difficulties, making it harder for some participants to engage socially. One participant reflected on how his mental health struggles affected his ability to form friendships in college:

> *'I just wasn't able to maybe make friends or function properly in college, socially, because of my mental health problems'* (P5).

Romantic relationships were something that did not often come up in the participants own stories. When asked most participants did not see any romantic relationships in their future saying they had no experience of personal relationships. Some said they would like to meet a long-term partner in the future but had no idea what that would look like. Some also voiced that society in general can often hold outdated views on disabled people in romantic settings:

> *'I think people…. when they see somebody maybe in a chair, they're sort of like, oh, yeah, like they don't have any real feelings or they don't exist, but that's not true at all.' (P1)*

One of the participants had tried the '*online scene*' but found it difficult to make a '*romantic connection'*. He described how it was:

> '*Constantly disheartening…to just not meet people, it was the conversation, it was quite hard, which just in general is difficult but, it just never really went very far.'* (P3)

He described how he gave up for a few years but decided to try again and he made a connection:

> ‘P*: But after a few years I went back to it, and I did actually meet someone.*
>
> *I: Yeah.*
>
> *P: She lives in X which is difficult, but we still talk*
>
> *I: Yeah, it's nice to be able to talk and share and just have a connection, isn't it?*
>
> *P: Yeah, it is, it’s great*
>
> *I: And are you still in contact with her?*
>
> *P: Yes, we talk every day, Yeah, it’s about four and a half years ago since I met her.’* (P3)

Another young man expressed how his lack of confidence and feelings about his attractiveness make it difficult for him to pursue relationships. He believed that the idea of a girl finding him attractive was unrealistic, which affected his self-esteem and willingness to meet someone. He shared how he often rejects himself before others can:

> *‘I don't have confidence in myself being attractive or a suitable match for lots of girls. I kind of reject myself before them because I just know that they won't think of me that way. I'm protecting myself a little bit, but mostly, no, that's the reality of how it is, I think.’* (P5)

Societal perceptions further compounded social and romantic relationship exploration for the young men with most participants describing experiences of being treated differently due to having a disability. They perceived that people make assumptions about their abilities, emotions, or personal lives. Such biases reinforced social isolation and reduced their sense of feeling different:

> *‘Just people who have disabilities don't have as many, don't see as many possibilities, maybe as other people. And we always feel different and are always maybe told by lots of people to manage our expectations. So yeah, in that way we just feel different from everyone else. And because we're not, because we're told we're different so much, maybe we just don't, don't do as well in life or reach our potential as much. Just because we're not supported as much as we could be I think.’ (P*5)

Enhancing awareness and understanding of the disability experience in the community is described as crucial to promote inclusivity and foster meaningful social connections. As one participant pointed out:

'Nobody really knows about things like Duchenne…. it's rare enough, so it's never really addressed…. even in the hospital, they would never have heard of it.' (P3)

There is limited media representation depicting the romantic lives or feelings of people with disability in general:

'I think in general, society has strange views on disabled people in romantic settings. Like it's not really depicted in the media the same way as any other types. Especially when I was younger. There are a few examples now but in general disability isn't, it's sort of regarded as you just don't have a romantic life in any way like, that was always my experience.' (P3)

Another young man shared how having role models who face similar life challenges could be inspiring for young people living with DMD. Reflecting on his childhood, he recalled looking up to many people, including celebrities, but noted that his role models were *'all very much the same... it wasn't like anybody in a chair or anything' (P1).* As an adult, he acknowledged that representation is *"getting better,"* and describes how he now has:

'a few examples of people who I love, who I sort of look up to. Maybe they don't have Duchenne, but then there are others who do, and I have looked up to them.'(P1)

4.5 Accessibility is the main barrier for Transition to Adulthood

Accessibility emerged as a barrier to successful transition to adulthood for young men with DMD. This section explores three subthemes - physical access to the built environment, access to transport services, and access to personal and healthcare assistants. The challenges shape the experiences of navigating social, educational, and community spaces for the young men.

4.5.1 Physical access

Infrastructure and building design play a pivotal role in accessibility within the physical environment for people with DMD, particularly as they typically rely on large power wheelchairs. While urban areas generally offer better accessibility, rural settings can pose significant challenges, such as the absence of footpaths on many roads. One participant highlighted this disparity:

'A lot of people unfortunately don't live directly in the middle of the city centre, where, you know, a lot of things are available to them. We, a lot of us. live in rural areas, so it'd be a bit different in trying to access things.' (P1)

Navigating outdoor environments in a power wheelchair can become even more difficult in poor weather conditions. Uneven footpaths, drainage dips, and other environmental barriers make navigation of outdoors spaces challenging. One young man described his struggle:

'The footpath itself isn't actually….. accessible. It's like the dishing at the end…. well it dips down, on both sides, because it's like a drain there, so… for most of it I have to reverse off. Or I have to just go down the road which isn't really the most safe thing.' (P6)

Beyond infrastructure, social spaces remain largely inaccessible, limiting opportunities for socialising. Many young men with DMD find it challenging to participate in typical activities, such as visiting pubs or nightclubs, due to physical barriers:

'Like trying to access things…. say going to the pub or going to the nightclub… access is the problem there. And I couldn't even tell you…. like nightclubs and stuff that are actually accessible. Or pubs as well. So that would be tough.' (P1)

As a result, most young men with DMD rarely go out alone. Safety concerns and accessibility limitations create additional barriers, making it difficult for them to navigate their surroundings independently. One participant shared his experience:

'I don't really like walking down the town in it. I don't feel very safe. (P2)

Participants acknowledged that while schools and colleges offer some support for accessibility, the complexity of DMD meant they continued to face daily challenges. Inaccessible doorways remained a common issue, with one participant sharing, '*Sometimes when you go in through doors, you get stuck'* (P2). Additionally, reaching buttons to open doors can be difficult, as another participant explained:

'The college itself is… accessible, like on most of the doors they have … low-down buttons that you can press to open them automatically, but it's not all of them.' (P6)

Taxis are provided to assist with travel to and from college, however this service was not always reliable. Some young men reported experiencing situations where *'the driver wouldn't turn up'* (P6) or transport arrived late, leaving them waiting as they didn't have alternative transport options.

Young adult participants expressed a wish for improved accessibility within social and college settings. One young man felt better '*design*' would '*help people do a lot more things*' (P2) with another suggesting a '*universal key'* like they use in other countries '*would be really helpful'* (P1) to facilitate improved access to disabled bathrooms within the community. Reliable and accessible transport options in both rural and urban settings was seen as important with one participant saying, '*I'd like there to be more transport'* (P2) in his hometown.

4.5.2 Transport access

Access to public and private transport presents significant challenges for adults with DMD. Private transport can be costly as families need to purchase adapted vehicles to suit a large power wheelchair. Two young men wished to pursue private driving lessons; however, the unavailability of accessible vehicles made this impossible:

> *'I was trying to learn how to drive, but they only have like one or two vehicles in the country, and they're broken. They haven't gotten it fixed for about a year. So, I haven't been able to do that. So, it's trying to be able to do these things, but not being able to access these services is a really big problem. Like you want to do things but like you're not able too' (P1)*

Buses are often inaccessible, with one participant stating he never uses them because, *'I wouldn't be able to get on it'* (P2). In smaller rural train stations, the lack of available staff further complicated travel plans, for example a lack of assistance providing ramps for boarding trains impacted independent travel. One young person described how he relied on his parents '*to always get dropped and collected'* at a main station *'because someone would come with the ramp*' (P1). These issues created challenges to routine travel plans which impact participation in everyday activities.

Taxi services must be pre-ordered by phone to ensure the availability of a vehicle with adequate space for a large wheelchair. More commonly used mobile app-based services are not always a viable option, as they do not allow users to specify accessibility requirements when booking. This became a challenge for one participant when his college switched taxi providers, requiring him to use a new app. He found it less accommodating than the previous service, explaining:

> '*you can only order a taxi like on the day when you need it, but em, I need to order them in advance.'* (P6)

4.5.3 Personal Assistant and Health Care Assistant access

Access to support services, such as personal assistants (PAs) and health care assistants (HCAs), was highlighted by participants as essential for promoting independence, reducing dependence on parents, and enabling greater participation in social and educational activities. However, securing adequate PA hours or HCAs within college settings proved to be challenging as experienced by a participating college student:

> *'they are quite helpful there, it's just well with most things, like since the start of the year…. I was supposed to have a HCA to help me…. with going to the bathroom and opening the doors, but….. that hasn't actually happened yet. Like instead I just got a PA that would help, but… they weren't permitted to actually help with the toileting which is… the main thing that I needed.'(P6)*

Another young man expressed how having PA support would enhance his ability to engage in more college activities and student life:

> *'I think… someone with my condition would benefit from having an assistant around the college—more like a personal assistant, I think. Because I think you need someone to be your, kind of, your arms and legs. So, I think you could be involved in more things in the college if you had a personal assistant.' (P5).*

Beyond college, PA support was seen as vital for maintaining independence and engaging in everyday activities. Limited access to PAs remained a key barrier to independence, as one participant explained:

> *'Better access to getting a PA would help because you can't really just go anywhere on your own. I really need full-time support—someone to help me with everything,'(P3).*

Another participant described how he would like PA support '*to basically do anything'* for him, to bring him '*places and stuff*' (P2) with another highlighting how the PA can support independence by reducing the support parents have to provide:

> *'It's not relying on your parents, even though my parents are very good to me, and they've always been like, "Oh, you do this, do that", I don't want that to be there. And I don't want that to be their type of thing that they have to do that.' (P1)*

4.6 Transition to Adult Healthcare Services

Young men with DMD discussed how they felt supported by the medical team in adult hospital DMD clinics, receiving regular medical appointments for respiratory and cardiology reviews. One participant described how for him '*It's good to get seen as often as you can, I think.*' (P8). It provides reassurance everything is ok:

> *'Like the last time I was there they were happy with where I am at the minute.*'(P8)

Most however perceived that the main purpose of the hospital clinic was to monitor physical health, and that emotional or mental health needs were not a priority. One participant shared how it can be difficult to bring up your needs and it's more of an *'afterthought'* from the medical team:

> *'P: It's sort of an afterthought that the doctors might have. Like if I haven't a doctor that asks about it and if I didn't ask about it, I'm not sure it would ever be addressed really.*
>
> *I: And it's not something that you would bring up yourself.*
>
> *P: No, it is hard to bring up.*
>
> *I: It is hard, if you're not asked directly, it's probably a hard thing to bring up.*
>
> *P: Yeah, it's quite hard to bring up.' (P3)*

Another young man described a similar experience where he would briefly be asked if he was '*okay*':

> *'" Are you okay?" Are you enjoying a few things in your life?" Are you able to work?" and then that's it. They probably don't ask about the mental aspects as much'. (P5)*

Another shared his experience of feeling supported medically however he noted a difference in the level of supports he received in the medical adult clinic as opposed to the children's DMD clinic:

> *'like before… everybody would have been in touch, like kind of once a month or every couple of weeks, but now…. the ones that are mainly in touch are usually just like the doctors in respiratory and in cardiology'. (P6)*

When considering the support received from the local community adult healthcare team's half of the men highlighted a lack of therapy support sharing that they '*haven't really had much contact with the physio or the OT*' (P6). One young man said that when he transferred to the local adult Primary Care team he found '*they weren't very helpful*' (P2).

The young men reported difficulties contacting professionals such as their occupational therapists (OTs), describing delayed responses or unreturned calls. This left one young man feeling unsupported sharing that, "*The OT I have here never answers when you try to contact*" (P2). Assessment and provision of necessary equipment, such as wheelchairs, was often described as a slow and frustrating process with half of the young men reporting long delays and inadequate responses when seeking assistance. One young man expressed frustration at his ongoing challenge of securing a new wheelchair saying:

> *'They're taking too long to get it. And they're trying to add new pieces to my old chair instead of getting me a new one'* (P2).

While another shared his frustration at waiting months for a new wheelchair or modifications:

> *'I've been waiting for a new wheelchair for maybe the last six or seven months.'*(P1)

Most participants reported having limited access to psychological support but described it as something that '*would definitely be helpful'* and '*definitely something I would have availed of*' (P3). Living with DMD was perceived to have an impact on emotional wellbeing as described by another participant:

> '*Because with Duchenne you are going to have a lot of trauma and that's just the way it is. You're going to have trauma with everything that's going on, but being able to talk through that and being able to have somebody there to be able to talk through it and get those feelings out there I think is very important.' (P1)*

Professionals providing psychological support are often perceived as having a limited understanding of DMD and its impact. One participant noted that those working in general services *"don't understand" (P1)* the challenges of living with DMD. Most participants identified the need for services that recognise and address the emotional and psychological challenges faced by people living with DMD:

> *'It's easier then to cope with these things, because your admitting it to yourself that it's actually going on, instead of building it up, so I would definitely say, if I was in the HSE I'd be fighting for that like.' (P1)*

With another describing how a holistic approach to support adults with DMD is not prioritised within current services to enable participation in all areas of daily living:

> *'That is one thing that isn't supported enough—people to have a good working life and a good social life. It's not prioritised near as much as it should be.'* (P5).

Young men with DMD expressed the need for better healthcare services that address their specific needs. They shared that general community-based healthcare teams were not providing enough support, with one stating, *'the general system just isn't enough for Duchenne'* (P3). They emphasised that having access to local healthcare providers who understand DMD, particularly during the transition to adulthood, would make a significant difference. As one participant explained:

> *'I think people need to understand the condition as well… You'd be more prepared for what was about to happen, probably.'* (P1)

Participants shared that they would like to see increased access to psychological support. While some services do exist, they were often described as '*not very helpful'* (P2). One young man shared how he paid for private support in the absence of a service for him:

> *'I tried counselling once for a few months, and I just paid for it.'* (P5)

4.7 Skills to support transition

Most young men identified several key skills and supports that would help them transition into adulthood. Confidence-building initiatives, such as communication skills training and tools for effective planning and organisation, were seen as beneficial. One participant noted that having a better idea of what to expect in conversations would help him feel more confident:

> *'If I could find out… what they were gonna ask…. I could think of something to bring up.' (P4)*

Planning and organisation skills were highlighted as essential for daily life. One young man explained the importance of *'thinking ahead'* when planning outings, such as checking whether there would be *"much walking involved or something"* and making necessary arrangements (P4).

Some expressed a desire to take control of their own lives and participate in decision making relating to their care needs and planning for their own future. One young man described how he found it challenging to make his own decisions:

> *'it was like I was in bubble wrap, you know, I couldn't make my own decisions or anything myself, and I just couldn't deal with that as a young person…… because I think people forget, people with Duchenne… we're like anybody else, you know, we don't have really any intellectual disabilities. So we're like any other people who can sort of make decisions for themselves. And that's what the problem is.' (P1)*

Encouragement from parents, teachers, and professionals played a crucial role in fostering self-belief and social participation. Participants stressed the need for adults to promote independence and avoid limiting expectations. One participant shared:

> *'I would tell other people, I suppose teachers, OTs, parents… don't limit their child as much, and let them think that they can have a life like everyone else does. If you don't have those supports, then you're not gonna be as confident or as outgoing. So those supports need to be there.'* (P5)

Workplace support was identified where participants felt they would benefit from the opportunity to discuss accommodations and expectations with employers before interviews. One participant suggested:

> *'I'd love for people with Duchenne to be able… to talk to somebody higher in that company first before they go for the interview. And then… have maybe somebody to go to, like an access officer or something.'* (P1)

Understanding rights and entitlements was also considered important. Knowing what services and supports were available would help young people make informed decisions and navigate daily life with greater confidence. As one participant explained:

> *'I think people don't know a lot of things about policies and everything. And it would be really good for someone with Duchenne to know, like, they do have the right to the service… even though it is hard to access, they do have the right.'* (P1)

Most participants identified the importance of self-confidence and the ability to assert themselves as important for transitioning to adulthood, as it can empower young people to communicate their needs, advocate for themselves, and take charge of their own life decisions. This is challenging for young men with DMD with one participant describing how most young people:

> '*wouldn't have the confidence or the skills to do that…. because you're so used to your parents doing it. So, I think it's just to have the confidence of being able to, like, say, you want to see this, you want to see that, I want to be in charge.' (P1)*

By focusing on confidence-building, life skills, workplace readiness, and understanding rights, young men with DMD felt they would be better equipped to transition into adulthood with greater independence and security.

4.8 Conclusion

This chapter presented the findings from interviews with the young men who participated in the study, exploring their experiences of transitioning into adulthood. They described increased dependence, emotional challenges, and limited opportunities for social participation. Accessibility issues—across physical spaces, transport, and support services—significantly impacted their access to further education, employment, and community engagement. While adult healthcare services addressed physical needs, access to psychological and therapeutic support was limited. Opportunities for social and romantic relationships were further affected by societal perceptions of Duchenne and participants' own lowered expectations. Despite these barriers, the young men expressed a strong desire for autonomy, highlighting the need for more inclusive, holistic systems that support independent living for individuals with DMD. Chapter five will present the findings from the analysis of the interviews with the parents.

5 Findings: Parent Experiences of their Son's Transition to Adulthood.

This chapter presents the findings from the analysis of the interviews with the parents. There were seven themes generated. These are presented in Table 5-1.

Table 5-1: Parent Interview Themes

Themes
1. Impact of DMD on Daily Life 2. Leaving school 3. Social and romantic connections 4. Accessibility barriers for Transition to Adulthood 5. Health and Social Care Supports 6. Planning for the Future 7. Transition Supports

5.1 Impact of DMD on Daily Life

Parents recognised the considerable challenges their sons faced in coping with the daily realities of living with Duchenne Muscular Dystrophy (DMD). They emphasised the progressive nature of the condition, describing it as '*a highly medicalised condition, which nobody gets better*' from (P11). Despite the complexity of the condition, most parents perceived their sons as being in good health and doing well day-to-day. One parent noted, '*he finds it harder when he gets a cough and cold*' (P10), while another shared how her son is particularly mindful of protecting his general health:

> *'So, it's constantly on his mind. And he's like, for you mam, like when you get sick…. you can get over it, but he doesn't get over it that easy'* (P13).

Health management routines, such as using a cough assist device or a nebuliser, have become an integral part of daily life. As one parent explained, '*we have everything that we*

need, and we use it' (P10) to maintain their son's overall health. Managing the medical aspects of their son's diagnosis was daunting. As one parent put it, she needed to be:

> '*on the ball with him, from a medical point of view, which is really hard, I'm not a medic*.'(P11)

During transition to adulthood all parents described how young men with DMD required increasing levels of support with activities of daily living (ADLs). Parents became the primary caregivers, where one parent described a typical morning routine as:

> '*Getting him up, dressed, fed—he can't do anything for himself. He can't brush his teeth, dress himself, or prepare his breakfast. He literally has me to do everything*.'(P11)

Parents perceived that this reliance on another person for daily assistance was challenging and frustrating:

> *'I think that is the most frustrating thing for him is that he is dependent on people for everything, all of his needs.' (P10)*

They also highlighted the gradual physical deterioration and loss of functional skills caused by DMD:

> *'Year by year, they get weaker, and they are able to do less and less. Like things he could do last year, he can't do this year.' (P10)*

Another parent expressed that one of the most challenging aspects that *'these young men have to deal with'* (P12) is watching their own bodies grow progressively weaker over time. Activities once enjoyed, such as gaming or building Lego, became harder as hand function declined. One young man, who loved building Lego, had begun to struggle due to his decreased hand strength. His father shared how difficult it had become to enjoy this activity together, as his son now observed rather than participated:

> '*He gets frustrated sometimes like you know, as I was saying to you about the, the Lego was the big thing. He bought a few boxes of Lego there recently. I said you have more work for me. He got a fit of laughing, he said but sure you don't mind, I'll make sure you don't make mistakes…… Some of it he can do himself, but you know the big ones where you have to press down, he wouldn't have the strength for it. It's tough to watch that but eh he says like I won't be able to do anymore of this, I'll let you do it.'(P9)*

This growing dependency on others was perceived by parents as frustrating for the young men. One parent described how her son faced increasing difficulty completing physical

tasks. He relied entirely on others for every aspect of his care, from wiping his eye to scratching his ear, leaving him with no independence:

> *'It's like his body isn't keeping up with his brain. His brain wants to do things, but his body won't let him do it. So, he found that frustrating.' (P10)*

All parent participants describe family as having an important role in providing both emotional and practical support for everyday life, including planning days out, ensuring accessibility, and stepping in when personal assistants (PAs) are unavailable. Some parents described their family as a strong, united team, where everyone works together to make life easier:

> *'And that is so important, because if you have the support around you, you're not doing it on your own. It's like a team effort. It's a family effort, and that makes the difference.'(P10)*

All parents perceived this family team approach was important in ensuring there was always someone for the young man to rely on, whether it's for planning outings or supporting with ADLs. However, not all families experienced this cohesive support. When there were gaps in familial involvement and support, it impacted both the young man and supporting parents. This is illustrated by one parent's frustration at a family member's unwillingness to help, despite living nearby:

> *'Not once did he pick up the phone and offer… do you need any help? Do you want me to do anything? Nothing. You know, it doesn't make sense to me at all. Why would you do that to somebody when you live two minutes down the road?'* (P12)

This lack of engagement not only disappointed the parent but also impacted the support network that is important for meeting the daily needs of the young adult with DMD.

5.2 Leaving School

Parents viewed leaving school as having a considerable emotional impact on their sons. The end of school represented not just a transition but also a significant loss of routine and community. One parent described how her son felt when leaving his school days behind:

> *'And I saw it when he finished his leaving cert last year. He barely ate for about 10 days afterwards. He was so upset. He cried every day for 10 days afterwards because he was going to miss school so much. He never cried before. It was a massive, massive loss to leave all of that behind him because he was so well supported in school. And he was surrounded by his pals every day and lovely staff*

and everyone who cared for him. And all of that ended the day he finished his last exam. And he literally lost his appetite for 10 days and I knew what it was, we just had to let it sort of pass.' (P10)

Upon leaving school, all parents actively supported and encouraged their sons to explore available opportunities. Among the seven participating parents, four had sons currently enrolled in education, two had sons who remained at home full-time, and one had a son employed part-time in a family business. However, some parents reported that in the absence of structured support, some young men found it challenging to establish a sense of purpose after finishing school, particularly if they had not completed their final exams. One parent described a situation such as this whereby a young man was:

's*itting at home and he's doing nothing. He is on PlayStation every day of the week; you know and it's not good.'* (P15)

The transition to college was often complicated by logistical and accessibility issues. Parents described their sons experiencing many challenges participating in higher education. Frustration with the DARE process was highlighted by two parents, including one whose son lost an entire year of college, and another who perceived that young men living with DMD:

"are not being accepted as readily as those with anxiety and depression and mental health problems. It's, it's just ridiculous. (P11)

Parents also described how young adults who do attend college can find themselves excluded from specific college class events or modules because accessibility needs hadn't been considered in the course design:

'The course…. like for somebody in a wheelchair you would have designed the course better. Like he's off on Monday's because the rest of them are going to the gym and they're going to the swimming pool, so therefore there's nothing that he can do…… Like I mean she knew she was having a disabled person in the course for that year. So why would you do that.' (P15)

While most of the young men were not employed, many had explored and discussed future job opportunities with their parents. Most parents however viewed employment options as limited due to workplace physical demands and insufficient personal assistant (PA) support. One parent expressed this challenge, saying:

'He'd love a job, but the logistics of paying for and finding a reliable PA make it nearly impossible.' (P15)

For many families, higher education was perceived to be the more practical and accessible option. Parents saw continued study as a way for their sons to remain engaged and pursue their interests, even if securing meaningful employment afterward seemed uncertain. One parent explained:

> *'I said, you can do as many courses as you wish, but then, I suppose, he'd love to be doing that drawing in a company or whatever… but is that really achievable?'* (P15)

When considering life after school parents shared their perceptions of independent living and what that might look like for their sons. The progression of the condition and the growing reliance on parents for daily support were major concerns. One parent described how she considered independent living wouldn't even be an option and assumed her son felt the same way:

> *'How can you even think about living an independent life when you're becoming more and more dependent?... I'm only surmising now but I would imagine that if I was in his shoes, I wouldn't even think of becoming more independent as concurrently I'm becoming more dependent.' (P10)*

Some parents emphasised the complexities of achieving living away from family and shared their perspectives on whether it was a feasible option. Two parents stated:

> *'I can't see that, but I know it does work for some people, but I think it probably depends on the severity of your disability.' (P15)* Another explained *'the way things are set up in this country, I don't think he could even aspire to that, to tell you the truth….I don't think it's worth the hassle.' (P10)*

Parents also highlighted the challenges of relying on carers and PAs, which raised doubts about the feasibility of independent living. One mother questioned how her son could truly *'live as an independent adult*' when his father still '*has to rock up to college'* (P10) with him every day. Another parent shared their worries about the reliability of care services, stating:

> *'You could be left for hours, and you're starving hungry, and you have to wait until your PA comes in and makes you a sandwich.' (P15)*

The shortage of suitable housing options was another concern:

> '*There are no bungalows being built anywhere. There's nothing designed for them*.'(P14)

Efforts to explore independent living through the County Council received no assistance:

'They don't get support in any of those things here…. you know, they ask why they are not this, that's why, because they get zero support.' (P14)

Despite these challenges, many parents expressed a desire for their children to experience independent living. One parent described how she had discussed her son's hopes of living away from home with him. She acknowledged that:

"He's in the wheelchair but he has the same ambitions as everybody else. If the opportunity came up and he wasn't too far away and he'd all the help and support and everything, I'm sure it wouldn't be a problem." (P13)

Another parent reflected:

'It's a huge risk and it's a huge worry. I'd take the risk though, for him to have a normal life to a point, that he might just have a bit of freedom from us.' (P11)

5.3 Social and Romantic Connections

Parents described how their sons often faced isolation and loneliness as they transitioned into adulthood. After leaving school, many lost touch with friends who moved on to pursue their own independent lives:

'it's just that since they have gone to college this year…. they are busy and you know, and they are out living their student life so…. They are out doing their thing. That's what I notice, they have been less and less on the PlayStation with him since September. It's really diminished.' (P10)

As friends moved on, parents felt their sons often experienced a sense of detachment from their local communities. One parent described how her son's school friends no longer visited or called, resulting in a lack of social interaction with peers:

'Like he hasn't got any friends anymore because his friends don't bother with him because they've all gone on and they're working and they've got girlfriends and stuff….. I don't think he is bothered, to be honest anymore. I think he just gets on with it. He's got, he's got his pets. That's why we got so many animals, you know.' (P12)

While maintaining existing friendships was challenging, most parents felt that making new friends was equally difficult for their sons. One parent described how societal perceptions created barriers, making it challenging for her son to form new social connections:

‘I think it's because he's in the chair. And I think when people look at him, they see the chair, they don't see him for a while, until they get to know him I suppose. And then once they get to know him, he gets to know them, then it's OK.’ (p13)

Many parents recognised that their sons often felt self-conscious in public spaces, particularly in situations where their condition became more noticeable. One parent described how his son became especially aware of himself when eating in public:

‘*He eats maybe a jambon or a sausage roll, you know, or a bit of a sandwich, and you have to cut it up and feed him. But he won’t eat on Thursdays because there’s a big crowd there, so he’s aware and conscious of that.’ (P9)*

Parents perceived a lack of peers with shared lived experiences contributed to their sons sense of social isolation as they transitioned into adulthood. One parent reflected on her son's sense of feeling different:

‘He doesn’t know where his place is. You know, he’s the only child in the whole of our town, which is a big town, in a wheelchair.’(P11)

For many young men, family members were their primary social circle, with siblings playing an essential role. Parents described how older siblings provided companionship, advice, and were often role models:

‘Like his two older brothers, who are there for him. P will go down to him every weekend, and they’ll sit and play Xbox or have a bit of craic. S doesn’t live at home anymore but comes in every weekend to spend time with him.’ (P10)

Most parents also shared their perceptions of their sons personal or romantic relationships. They described conversations with their sons about girlfriends. Their sons had expressed a desire to form romantic connections, but they did not necessarily see relationships as part of their future. The young men expressed doubts to their parents, asking, *"How would a girl like me?"* (P10) or “*Mam, do you think I'll ever have a girlfriend?*” (P13).

One parent commented on her adult son being surprised to learn that someone he knew socially, with a similar condition to his, had a girlfriend:

‘*I think he's a wee bit shocked—do you know, that X has a girlfriend.*’ (P15).

She felt this wasn't something her son had ever considered as a possibility for himself. She also shared how she wasn’t sure how she would feel if he was in a relationship, admitting that she would likely be more protective of him than she had been with her other sons:

'I probably would be more overprotective. Just that wee bit more maybe than you were with the others. Just that wee bit more yeah.' (P15)

Most parents described how their sons wished to be recognised for who they are, rather than being identified primarily by their disability as they grew up. They wanted to fit in with their peers rather than be grouped with others solely based on having DMD. While this was not identified by all parents one parent recounted a conversation with her son about socialising with others who have the condition:

'Just because I have Duchenne and I'm in a wheelchair, it doesn't mean I have to hang around with people who have Duchenne. He said I don't want to be going out with these people just because we all have Duchenne. We have nothing else in common.'(P10)

5.4 Accessibility Barriers for Transition to Adulthood

What was common and strongly present across all the parent participant interviews was the impact of accessibility challenges within nearly every aspect of daily life for their sons. A frequently mentioned concern was the shortage of suitable, accessible bathrooms. Many parents repeatedly described these facilities as inadequate, with one parent sharing:

'I went to look at the wheelchair toilet… You wouldn't have swung a cat in it. The poor chap wouldn't have got his chair in the door.' (P13)

Many social venues had this issue, turning outings into frustrating and, at times, undignified experiences. One parent described:

'*We were at a gig up in one of the pubs here in X. And he had to pee outside. We had to go in where all the kegs were, and now he didn't mind, you know, but... You'd like to have privacy.' (P13)*

To minimise accessibility issues, parents often researched venues in advance, knowing that most bathrooms lacked hoists or enough space to close the door once a wheelchair was inside. Recreational and community buildings frequently lacked accessible bathrooms, making it difficult for their sons to participate in social activities. As a result, socialising independently remained a challenge. One parent described how her son had to leave a night out early due to inaccessible venues:

'*They were all going to a pub, so his daddy had looked, and the pubs they were going to weren't wheelchair accessible, so he had to come home.'(P15)*

Many parents noted that their sons often avoided social spaces such as pubs, as they were often inaccessible or uncomfortable. One parent noted that her son found it difficult to be heard in noisy pub settings, while another parent reflected on his son's attempts to socialise, only to find that accessibility barriers made it nearly impossible:

> *'He looked to do some of the things involving the pub… to try and, you know, socialise or whatever else, but in the end, it was just a bit too difficult for him.' (P14)*

Even basic tasks such as shopping posed accessibility challenges. Half of the parents specifically mentioned the barbers as being difficult to access:

> *'A lot of the time there's no ramp; there's no doors and stuff like that. You can't get in there, like the Barber shop. There's no way you can get in… we have to find somewhere with the big door so you can get it. And that's not easy either, you know.'*(P12)

All parents also described challenges for their sons' navigating roads, footpaths, and public spaces further limiting independence. Parents described how they accompanied their sons outdoors because:

> *'You have to go out on the road and then he starts to panic because he thinks he's going to get rundown' (P*15) or *'sometimes you might get to a place….and you know, you come down off the path but the far side of the road, you can't get up because there's a curb*.' (P13)

Unreliable transportation was perceived to hinder independence, with all parents reporting that their sons depended on them for travel. One parent explained how his sons had tried using local public transport but found it inaccessible, with '*zero support available*' (P14) to make it feasible. Parents also shared that their sons had hoped to learn to drive, but this opportunity was no longer accessible due to a lack of available services. As one parent explained:

> '*there's no place in the country that does it except for X and they had cancelled all their driving lessons during Covid and they haven't brought it back yet*.' (P14)

Private taxis were funded, and available to support young men with DMD, in getting to and from college. While parents acknowledged this was a valuable form of assistance, they also highlighted its limitations, including frequent delays and unreliable service. The pre-booked nature of taxi services restricted social opportunities, leaving little flexibility or opportunity for spontaneity to participate in activities beyond attending lectures. One father explained:

> ‘*He wouldn’t have the same experience at all, socialising, because basically we leave here at 8am for a lecture at 9:00 and at 1:50 it finishes and we're back in the taxi 2.30 at the latest you know.*’ (P9)

Young men with DMD require larger, wheelchair-accessible vehicles to accommodate their power wheelchairs. However, purchasing adapted vehicles posed a significant financial and administrative challenge for families. Two parents expressed that they **‘**c*ouldn’t afford’ (P13)* accessible transport, while another applied for support but was repeatedly denied, explaining that ‘*everything is means tested*’(P15). Another parent compared the situation to other countries, where transport grants allow young men with disabilities to lease adapted vans for self-driving. Unfortunately, he reported this support was not available for young men with DMD in this country:

> ‘*There’s no such concept of a transport grant here for Duchenne kids*.’ (P14)

Attending hospital clinic appointments required the support of parents with some parents citing inadequate parking and a lack of accessible changing spaces as issues. One parent shared the challenges he faced when parking at clinic appointments:

> ‘*All of us in blue badges, who drive these massive vans, that can't fit in anything like you know, so we can't even fit in a normal car park.*’ (P14)

While another described how ‘*there's no changing places, there’s hardly any wheelchair spaces in X (adult hospital)’* (P11). A parent also shared how appointment letters and communication is via postal letters which most men with DMD are unable to access and read removing opportunities for self-control:

> *‘The only way they get stuff is in postal mail, on paper or whatever else. It's useless to the boys. It's useless, they don't even look at it. They don't open envelopes; they don't open packages. They…. can't basically, you know, so that, you're already shutting them out completely before you even start the questions you know.’ (P14)*

Access within college and university settings was another concern, with issues such as lifts, doorways, and library accessibility all impacting the ability to pursue an independent student life. One parent explained how his son always needed someone with him:

> ‘*He does need someone with him all the time you know, as I say to open the door, if he wants to cross at the lights someone has to press the button. That kind of stuff like you know so.’(P9)*

Although lifts were available on campus, decreased hand function presented challenges. As one parent noted:

'*He can't raise his hands. He can't actually press the button to get into the lift, or to call the lift. He can't press what floor he wants to go*.'(P9)

The difficulties extended to doorways that weren't wide enough, "*big fire doors*," and wheelchair-accessible toilets with heavy, press-to-open mechanisms:

'Even the ones that are press to open, sure he can't even raise his hand or hit his hands to open any of those doors you know.'(P9)

Additionally, a parent supporting his son at a university described issues in the library, noting that '*they just had the physical book*' (P9). The lack of accessible e-books meant the family had to scan physical books at home. During a meeting with the librarian about e-book options, he explained, '*look he can't turn the pages, he can't lift his hands*,' (P9) which then led the disability officer to ensure that he received the necessary materials.

Parents also cited challenges in accessing assistive technology (AT), as one parent said, '*there is very little AT support*' (P11) with another describing how her son was left without AT in school and college:

'He never got a laptop… he's never been able to get one. They've all said, oh, we'll get you one, it never happened.'(P12)

5.5 Health and Social Care Supports

Parents consistently described the transition from child to adult healthcare services as fragmented and poorly coordinated. Many shared frustrations about how the process differed depending on the hospital, leading to confusion and delays:

'Half the different hospitals transition at different times…. Some don't accept you after 17, while others won't take you until 19. And, you know, X will keep you until you finish school.' (P14)

Once transitioned, delays in being picked up by adult teams were common. Parents described how '*multidisciplinary care'* (P14) services, like physiotherapy and occupational therapy were often unavailable, resulting in gaps in care:

'We don't have physio, we don't have OT and other things.' (P10)

All parents expressed frustration with both children's services, such as the Children's Disability Network Teams (CDNTs), and adult primary care teams. Long wait times, poor access to equipment, and a lack of professionals with expertise in DMD were frequently

mentioned. One parent expressed frustration after her son was provided with the wrong equipment from his CDNT, saying:

> *'I don't have time for wrong equipment and wrong measurements and bullshit.'*(P11)

Most parents perceived the teams are primarily reactive rather than proactive, with one parent describing the approach of the CDNT as mere "*firefighting*":

> *'They're only solving problems or ordering equipment. That's all they are doing. Nobody's fault… sometimes you get people who haven't a clue about Duchenne and don't bother learning about it, so they're no good to me.'* (P11)

Ultimately, many parents expressed that the lack of expert guidance leaves them to take on the role of researching and advocating for their son's needs:

> *'there is very little coming from the experts and it ends up being…. the mother or father who just gets so frustrated and comes to a decision that you need A, B or C and then goes to look for it.'* (P11)

Parents' experiences with adult services were mixed. Some shared encounters where poor communication caused unnecessary worry:

> *'She made out that it was some sort of torture thing, and he was worried to death about it. Then another OT came, and it was so straightforward and easy.'* (P12)

In contrast, another parent shared a positive experience, highlighting the difference that a responsive and supportive OT made after their child transitioned to adult services:

> *'You know when you get somebody good, it makes a difference. Our new OT, I suppose since he has moved to adult services, is actually lovely… she is usually our first port of call… she actually answers the phone when you ring her, and if she's not available, she rings you back. Something as simple as that.'*(P15)

Despite these differing experiences, all parents agreed that services are significantly under-resourced. Many expressed frustration over the lack of timely support, often feeling left to repeatedly chase responses:

> *'You're just left to ring and ring and ring and ring.'* (P11)

Obtaining consistent PA hours was a further challenge. Parents viewed PA support as essential for their son, emphasising that they '*need to be with a personal assistant'* (P15). However, they also described how you have to '*fight for every little part of it'* (P10) in a system where '*the hours aren't there*' (P15).

In educational settings, parents highlighted the challenges of securing consistent and reliable PA support. One parent shared his son's experience of PA support in university:

> *'They were chopping and changing. There were four different PAs before Christmas, and then a different person for the exams. He had to explain to everyone what the story was. Then they send in a HCA for the exam, and you're saying, look, he can't lift his hands—if his glasses fall, you have to fix them. It's just kind of totally haphazard.'(P9*)

Another parent voiced concerns about the lack of backup plans if PA support failed to show up, emphasising that '*he can't be without a PA*.' (P10)

While most parents provided personal care support themselves, two families arranged for HCAs to visit their home. These parents encountered similar reliability issues, often having to coordinate holiday cover with care agencies. One parent explained that if the carer doesn't arrive, '*he is unable to get out of bed*.' (P12)

Some parents admitted to feeling reluctant to engage with discussions around transition during their time with children's services. They valued the familiarity and coordination provided in children settings:

> *'I don't want it to be brought up, because I'm quite happy the way it is at the moment. I'm happy seeing them all on the one day, in one place with the changing places.' (P11)*

While another shared her initial impression of the adult clinic and how she found it '*totally different'*. She perceived children's clinics to be '*more you know, caring'* and initially struggled, finding the adult clinic '*you know like it's mental', 'it's grown up'* and this was difficult because she was still thinking of her son as her child:

> '*Because you still probably think of them as your child you know. Like they are* still a child.' (P15)

5.6 Planning for the future

All parents described the essential role they played in supporting their sons as they navigated the transition to adulthood. From coordinating healthcare services to securing post-school educational opportunities, parents described how they took on the responsibility of advocating for, and managing, their sons' futures. Many expressed frustration at the lack of specialised support available to young men with DMD during this period. One parent summed up this gap by saying:

'There was nobody facilitating that at all…. In essence, we're like the transition at the moment right. The parents are doing everything.' (P14)

Without structured or co-ordinated transition services, parents found themselves taking on the roles of advocates and coordinators, juggling paperwork, organising equipment, and liaising with multiple agencies to ensure their sons' adult needs were met. One parent described how he was constantly on the phone:

'If I had to tell you the number of times I had to ring people about different things for the lads, you know, I'd be on the phone all day like, you know. And I am on the phone all day.' (P14)

Another parent reflected on how providing this level of support consumes so much of her time. A lot of time is spent liaising with services and advocating for her son's needs to be met. She perceives from her interactions with services that she cannot expect somebody to pro-actively organise what needs to be done to facilitate transition to adulthood for her son. She spends most of her time advocating and coordinating for her son's needs:

'I try to take….. a non-Duchenne day a week, where I don't make any phone calls…. But today I think I had to make 2 or 3 emails about X. You know you can't just expect or hope somebody will just pick it up and do it.'(P11)

While all parents described how they assumed responsibility for the transition process, only three reported they sourced transition toolkits which they used with their teenage sons describing them as: '*a whole kind of questionnaire about things…. it's like a checklist of things.' (P14)*

Parents have different outlooks on how they approach and prepare for their son's future. Some take it one day at a time, focusing on immediate needs and avoiding overwhelming thoughts about what lies ahead:

'*We just go for one day at a time… getting through tomorrow… because overthinking it can drive you crazy*.' (P9)

Others, however, find the uncertainty about their son's future distressing. The thought of managing increasing care needs, dealing with changing support systems, and facing the realities of a life-limiting condition can be overwhelming. One parent expressed her fears:

'*Nobody gets it about Duchenne… so that's the dread of the future. The dread of us not being able to cope, and constant changing carers, and increased hours of carers… For me, I worry about, as I get older, how on earth I am going to manage*

to do 24/7 care… And then at the back of your mind, he could die at any time… if I thought three years down the line, five years down the line, I might go mad.'(P11)

Despite this, most parents were focused on day-to-day living rather than dwelling on limitations:

'*There are obstacles, but you just deal with them.' (P10)*

At the same time, they recognised the need for forward planning due to the progressive nature of DMD. As one parent put it:

'*With Duchenne, you have to be six months ahead of yourself.' (P11)*

While acknowledging the difficulties, parents consistently expressed a desire to ensure their sons led fulfilling and happy lives. One parent described the family's commitment to positivity following their son's diagnosis:

'His dad and I said, we will just make every day a happy day. And that's what we did. And that's always the first thought every day, to make every day a happy day. As long as he is happy.' (P10)

5.7 Transition Supports

Parents highlighted the importance of fostering independence and empowerment as their sons transitioned into adulthood. Most described how they actively encouraged their sons to take part in decision-making, manage their own medical information, and advocate for themselves in both healthcare and educational settings. One parent described how she prepared her son to become more confident during medical appointments:

"I'll say you know the way we're meeting whatever doctor, and this has been causing an issue, or you are due to go in for an infusion. I think we need to speak to them about that, and I'll often discuss it with him before I go in….Because sometimes he will sit there and go "Huh". So a lot of the time it will be both of us talking but I will have spoken to him beforehand. But we are moving towards him talking more and getting his point across." (P11)

Some parents also recognised the need to prepare their sons early for working with PAs and integrating support into their daily routines. One parent reflected on the balance between caregiving and encouraging autonomy:

'So yeah, I think you've to be very honest and open from a younger age, you know that as you get older I am going to have to hand over a little bit of your care to other

people. So that I can keep caring for you in every other way, or I will burn myself out.' (P11)

Many of the parents spoke of the challenges they faced in stepping back and encouraging their sons to take more responsibility as they moved towards adulthood. This shift required support for both parents and young men in adapting to changing roles and developing communication skills:

'I was talking to them myself the other day. Like, just the, the kind of the role of, how do you go from, you know, when they're younger, you're like a parent, parent, parent, and a carer, carer, carer. But how do you, you know, pull away and let them have more independence?'(P14)

Several parents emphasised the need for specialised clinics with professionals experienced in DMD, highlighting that multidisciplinary teams provided comprehensive medical, social, and psychological support. Some families felt supported by occupational therapists (OTs) who provided valuable guidance, such as preparing families for future transitions or assisting with the adaptation to college campus facilities:

"His OT, she did that, and she gave me a transition workbook as well…. We would have had that conversation with our OT. She was the one, she was the one person that guided us through everything." (P10)

Some parents felt that having a dedicated transition coordinator would greatly benefit their sons, particularly someone who understood DMD and could assist with transitions. They envisioned a role that would include planning for PA support, education access, equipment needs, and independent living skills. They suggested having a single point of contact to handle day-to-day queries while also providing parents with reassurance and continuity of care. One parent described how a co-ordinator could:

'tell him what's out there, you know tell him that there might be a chance of a PA who could bring him places. You know sort out things like his laptop and look at where he is going to.' (P11)

A coordinator would also provide much-needed support for parents, as they strive to manage the daily care needs and co-ordinate transition to adult life for their sons:

"I'd love to have somebody just at the end of the phone that would answer the call, and then I can say what I need to say and whatever, you know" (P13)

Some parents highlighted the need for structured guidance on further education and career planning, particularly in understanding and completing application processes such

as DARE. One parent who struggled with the process suggested a coordinator could assist by:

> *'Taking an application, checking are we missing something here…. There's nobody that doesn't want to get a form in quickly, you know what I mean.'(P14)*

Most parents who participated said their sons had not accessed transition toolkits routinely within formal transition support programmes, however a few parents sourced independent transition toolkits which focused on building self-management and life skills. These toolkits were perceived by parents as a valuable resource when they addressed broader aspects of adulthood:

> *"It goes through a whole load of different things, you know, college, independent finances, all that sort of stuff. Housing. How do they feel? How do you feel that kind of thing… it's like a checklist of things in these different areas."* (P14)

5.8 Conclusion

This chapter has presented the findings from the interviews with the parents who participated in the study, exploring the parents' experience of their sons' transition to adulthood.

Parents described the challenges of increasing physical dependence and fragmented health and social care services. Leaving school often brought a loss of structure and friendships, while opportunities in higher education and employment were limited by accessibility barriers and inconsistent PA provision. Wider accessibility challenges—across transport, housing, and community spaces—further restricted independence and participation. Parents identified the need for coordinated transition supports, accessible environments, and specialist guidance to support young men with DMD transition to adulthood.

Chapter six will present the findings from the analysis of the interviews with service providers.

6 Service providers perspective on current service provision and supports during transition to adulthood

This chapter presents the findings from the analysis of the interviews with the service providers. There were three themes generated. These are presented in Table 6-1

Table 6-1: Service Provider Interview Themes

Themes
1. Healthcare Services and Supports - Management of Physical Health is prioritised - Recommendations for Supporting Healthcare Transitions 2. Resources and Service Providers Impact on Transition - Recommendations to Optimise Resources & Support Staff 3. Supporting the Transition to Adulthood Journey - Recommendations Supporting Transition

6.1 Healthcare Services and Supports

The service provider participants described how persons with DMD were supported through medical, consultant-led multidisciplinary teams, which provided essential medical care, in both children and adult healthcare services. Medical appointments were described as being scheduled '*on an annual basis or six monthly or 9 monthly basis'. (P19)*

Community based healthcare teams included the Children's Disability Network Team (CDNT) and the Primary Care Adult teams, which are not disability specific teams. From the participants perspective, both teams primarily supported the young person and the family in relation to deteriorating function and changing equipment needs such as '*hoisting, tilt-in-space shower chair, a comfort seat.' (P17)*. Across community teams all participants perceived that only urgent '*P1 needs are being met, for their equipment and their medical needs'*, otherwise their care episodes 'sta*y closed until a piece of equipment breaks…. that's what it is right now'. (P17)*

A significant challenge identified by services providers was the lack of adult disability services in the community. One service provider spoke about the difficulties associated with the '*transition to an adult disability team which doesn't exist and still doesn't exist' (P24).* She perceived there was:

> *'An awful lot of stress around the young adults transitioning into adult services because there wasn't a service, and community services didn't feel adequately equipped to meet the needs of people, young people with disability at that level.' (P24)*

The current support for transition to adulthood was described by all participants as a service level transition, that is the '*general transition from one service to the other' (P16).* The CDNTs provide universal supports for all children within the service, however this can minimise the opportunity to address the specific and individualised needs of young people with DMD with one participant describing:

> *'there are universal groups to support children for transitioning to adulthood but that's for children with autism, children with physical disability, children with muscular dystrophy, so it's not specific, diagnostic specific or client specific, so it's just general support for transitions'(P16)*

The participant OTs emphasised that their primary role in preparing young people for the transition out of children's services was to review and update enabling equipment. The role of the Occupational Therapist (OT) on the specialist DMD children's team was to review functional care needs, including equipment provision for mobility and daily living, assistive technologies, and environmental adaptations for homes and educational settings:

> *'a lot of that time is spent information gathering and checking if they have the correct equipment in place and that correct housing adaptations are ongoing.'(P19)*

Most service providers reported that the focus for all teams was primarily '*just making sure that the wheelchair is OK.' (P19)*

6.1.1 Management of Physical Health is prioritised

All participants perceived that healthcare services for adolescents and young men with DMD remained primarily focused on managing physical health, with limited attention to social care, psychological support, and community integration. The broader aspects of

transitioning into adulthood, including identity, independence, and emotional well-being, were often overlooked:

> *'The broader sense of transitioning to become an adult and what that looks like wasn't considered.'(P19).*

Mental health support was perceived to be particularly lacking within neuromuscular services, with one participant describing psychology services as '*absent from neuromuscular services'* (P23). Additionally, service providers identified a gap in OT support, perceiving it to prioritise medical needs, with insufficient attention given to family dynamics, social participation, and community inclusion. An OT described the lack of attention paid to the:

> '*social care aspect that goes beyond disability, encompassing family dynamics and community integration' (P24).*

Service providers perceived that the progressive nature of DMD contributed to increased anxiety, yet they noted that emotional well-being was rarely prioritised in clinical appointments. Instead, consultations remained centred on medical management with one OT describing how clinical priorities generally focused on physical areas such as '*ranges of motion… their ability to lift their hands above their head,'* (P19).

Most participants believed that identifying emotions was challenging for the young men within clinical settings. They often struggled *'to acknowledge and understand'* their feelings and *'to be able to explain to other people how they're feeling as well'* (P24).

The psychological aspect of living with a life-limiting condition was rarely acknowledged in appointments, as one participant shared:

> '*I know for a couple of them that they had friends on say football or basketball teams that passed away. And there's the whole life limiting aspect of the condition that just wasn't really addressed.'(P24)*

6.1.2 Recommendations for Supporting Healthcare Transitions

Service providers believed that the establishment of dedicated adult multidisciplinary teams (MDTs) would be beneficial in addressing the complex needs of individuals with DMD. They emphasised that a coordinated approach, like that of CDNTs, was necessary to ensure continuity of care, involving key disciplines such as social work, occupational therapy, physiotherapy, and psychology:

> ‘*They really need an MDT approach. Like it doesn't make sense for them to go from a CDNT… that has an MDT approach, for them to transition to like primary care service where all their disciplines are working separately when they've such high needs. They need all the team, social work, OT, PT, psychology.’ (P16)*

Another suggestion proposed by many service providers was that a young adult team, extending care from adolescence into the mid-20s, would be beneficial for individuals who do not fully fit within either children or adult services:

> *‘It’s almost like teenagers don't really fit in a paediatric setting but also don't really fit in an adult setting. If there was a young adult team, maybe for 14/15-year-olds up you know’. (P24)*

Such a team could provide specialised, consistent and structured support for adolescents during this critical transition period:

> *‘Like a specialist service where you could give proper time and have a proper plan.’(P17)*

All participants agreed that support should be person-centred and tailored to the individual, rather than following a universal approach. They believed interventions needed to focus on:

> ‘*The young man that is…in front of you… and what it is that they need,’ (P18)*

This approach avoided a *“one-size-fits-all”* model (P18) with targeted support being viewed as a more beneficial approach for young men with DMD as they transitioned to adulthood:

> *‘so even if you take two children with DMD, they're going to be different in their presentation or their skills and everything, so it needs to be really targeted, client specific supports to support them.’ (P16)*

6.2 Resources and Service Providers Impact on Transition

Service providers perceived that they faced several challenges in supporting young people with DMD during the transition to adulthood. Limited staffing and resources often restricted their ability to address all needs. The absence of psychological support on multidisciplinary teams impacted service provision, with one participant describing how she felt *‘unprepared’* to ask certain questions ‘*without the full support of a psychologist on the MDT team.’ (P19)* She compared it to:

'opening a can of worms without knowing whether they were going to get help with these things.' (P19)

There is a perceived lack of knowledge about DMD, particularly regarding its progression and transition-related goals, especially within CDNTs, by service providers. They highlighted challenges in the service delivery model, noting that clinicians involved in the transition to adulthood typically had experience working with either children or adults, but not both. One participant described how she:

'*had no real knowledge of what was out there beyond children's services.'* (P24)

Many of the service provider participants perceived that the lack of communication between children's and adult community services affected young men's experiences with health services during their transition to adulthood. They attributed a lack of meaningful referrals for transition and adulthood support to a lack of communication, or an absence of any pathways to support transition between the teams. A CDNT service provider participant indicated that once young men left their service, they had no insight into '*what they all went on to do'* (P16). The participant remarked:

'They leave the services, there's no communication. There is no follow-up' (P16).

An adult community service provider noted that referrals from CDNTs were typically limited to equipment needs, with little attention to broader transition support:

'*Generally it's when those children come into adulthood, they get referred to us…. it could be for following on for splinting or for seating. Generally, very few referrals if any about any vocational or any sort of further education or anything like that…. There doesn't seem to be a pathway.'* (P17)

The lack of a structured transition pathway combined with limited awareness among children's teams of what adult services were available to meet the ongoing needs of young men with DMD compounded the challenges of transition to adulthood. A CDNT service provider described this saying:

'We had no real knowledge of what was out there beyond children's services. When they're discharged, it's handed over to adult services.' (P24)

Overall, many service providers emphasised that the existing communication and referral process supporting transition to adulthood often leaves young people and their families without adequate support as they move into adulthood.

A factor influencing many clinicians' approach to transition planning was their natural inclination to remain *'as positive as possible'* when setting goals. One clinician described

how she focused on achievable childhood goals because, *'you're only working to 18.'* She admitted that adulthood goals were not considered because, as a therapist, *'you probably don't really want to go beyond that in your head, you know.' (P24)*

Similarly, another therapist reflected on the limitations of children's services in preparing for adulthood: *'We don't really talk about what life as an adult is going to be.'* (P19) She further elaborated:

> *'there's not much of a discussion about future plans…. what they hope to achieve or what their goals are…. I haven't had the opportunity yet to get into discussions about college with any boys with DMD or further education or you know jobs. That hasn't, that hasn't come up.' (P19)*

Fear and discomfort surrounding the life-limiting nature of DMD also influenced providers' willingness to engage in adulthood planning. This reluctance resulted in unmet needs for holistic and proactive support during this critical stage:

> '*I think the staff are afraid of it a little themselves you know', (P16)*
>
> *'I think everyone's terrified of the diagnosis and the fact that it is life limiting.'(P23)*

Service providers also highlighted the emotional challenges faced by clinicians working with individuals with DMD, particularly due to the progressive nature of the condition and resource limitations. One participant described feeling unprepared for the emotional toll:

> *'I remember I had three children… and all three of them deteriorated at almost the same time frame. And I was really upset about it. And I don't think there's anybody to prepare the therapist too because you are still seeing these children, so I don't think there's any supports in place currently to support any of those aspects.' (P16)*

6.2.1 Recommendations to Optimise Resources & Support Staff

Additional resources were perceived as essential to fill existing gaps and create a more holistic approach to transition planning. Service providers emphasised that specialised and experienced therapists with in-depth knowledge of DMD were essential components in teams supporting adolescents and young adults with DMD. Expertise to address the unique and evolving needs of individuals with DMD, particularly in areas such as seating, postural management, and caregiver stress were identified as was having clinical expertise in managing the progressive, life-limiting nature of the condition:

> '*with the life limiting nature of it, and just when to step in and went to start having conversations….. and acknowledging the carer stress as well.' (P17)*

A service provider also stressed the importance of community teams having experience and knowledge of DMD to effectively support the transition to adulthood:

> *'You know, DMD is very specific, and it has different needs… It needs to be something specific for them, it really does.'*(P16)

The importance of collaboration among different professionals to prevent fragmented care was identified:

> *'As a group of clients that just have so man*y service providers….*and everybody's doing different things,' and* '*it's the cohesion of everybody I think is really important to be able to ease that transition'. (P18)*

Service providers suggested that a structured and shared pathway linking children's disability teams and adult primary care teams would create a smoother and more coordinated transition process and enhance communication between teams:

> *'It would be maybe an opportunity to have something like that, a pathway, but linking with network disability, you know as they approach that adulthood….. I do feel it would be something that primary care could explore.' (P17)*

Supervision, team processes, and emotional support for therapists were identified and perceived as important in supporting service providers. One participant voiced '*that this is not an easy area to work in'* and described a challenging situation for a clinician working with DMD:

> *'a clinician who is, you know very, very confident and has great emotional capacity but is absolutely burnt out with the lack of resources and then they're trying to meet the challenges of someone who is really struggling in the medical environment that they're in, the caregiver or young person with Duchenne.' (P23)*

6.3 Supporting the Transition to Adulthood Journey

Most participants viewed the transition to adulthood as a process of maturing, with some young people '*more ready for adulthood than others*.' (P16). They emphasised that this transition was challenging for all young people, not just those with disabilities:

> 'B*ecause you think of any, any child right, who is 18, without a disability, they're not able to navigate all that at 18 either so they, you do need guidance'. (P17)*

Despite these challenges, participants perceived that young men with DMD should have access to the same opportunities as their peers:

> ‘It *should include everything that another person entering adulthood should experience.’ (P19)*

This included opportunities to live independently from their parents, and the ability to set personal goals for participation and engagement in daily life:

> *‘Young adults should be responsible for his own money and responsible for paying his own bills, you know even organising their own transport to and from, not only medical appointments but even to the cinema for the likes of that you know. It's just giving them the opportunities.’ (P20)*

Communication within clinical environments during transition was perceived by most service providers as a challenging dynamic between the service providers, parents and young men themselves. Conversations were generally directed toward parents, with many young men deemed to take a more passive role in healthcare discussions:

> ‘*Most of them are more passive…. they're given the opportunity but whether that could be done in a better way, could probably be looked into*.’ (P19)

Some also perceived that there was a sudden shift in responsibility when these young men moved from children to adult services, where they were expected to advocate for themselves. However, they questioned whether the young men were sufficiently prepared for this change:

> *‘But it was never about setting goals for him, about his own I suppose sense of self and about what did he wants out of his day, and stuff like that. That just never would have come up.’ (P17)*

Many service providers also identified parental involvement as both supportive and restrictive during the transition to adulthood. While parental care was essential in earlier life, it was perceived that it often delayed the development of self-advocacy skills, making it difficult for young men to take ownership of their decisions in adolescence and adulthood:

> *‘Mum or dad will take control for the first 15 years of their life, so like then relearning how to advocate for yourself at a later age becomes more difficult so that may require actually more standard coaching on that.’ (P23)*

Additionally, participants perceived that services did not sufficiently address the evolving dynamic between parents and their children, leading to difficulties when young adults began asserting their independence:

'it's more about his transition to adulthood and his own voice and his mum's role as a carer…. who is making decisions because he's now making his own decisions.' (P21)

Parents were often seen as *'more protective'*, while young men with DMD were sometimes perceived as *'not quite as streetwise and independent'* (P24) as their peers. This was perceived by the service provider participants as often resulting in young men lacking experience in navigating everyday responsibilities.

Service providers observed that parents themselves felt unsupported by clinical services during this transition. One provider highlighted a mother's frustration with the lack of guidance:

'that mum felt it and she voiced it' (P20)

Another provider acknowledged that resource limitations restricted what services could offer to parents, leaving them to navigate much of the transition process alone:

'*I don't think there's enough done for the parents to be honest but again we are limited in what we can do and what we can offer and with the resources.' (P19)*

Service providers also emphasised that access to information about community resources, housing, and vocational programmes was limited. One CDNT attempted to address this gap by organising an information day, aimed at connecting families with available adult services:

'We were really trying to look at that and get started… trying to organise for the teenagers coming towards discharge… an open day type thing where we tried to gather all of the services, get people in from the different adult services, that the parents and the young people could come and see what was out there.' (P24)

However, this was not identified as something that was done in any of the other service provider interviews. All service providers reflected on existing challenges in accessing relevant information. One participant noted:

'It's very hard to source information. Even as an OT, it's hard to source information. You know, you get general leaflets or stuff on the HSE website, but there's no number. You have to look up in your area, and not all areas have that service… And there is nowhere to actually find it easily.' (P24)

As the young men transition to adult primary care teams referrals received were typically limited to equipment provision, rather than skills development for independent living:

> '*Very few referrals if any about any vocational or any sort of further education or anything like that'. (P17)*

An OT working on an adult primary care team reported that requests for support rarely focused on increasing participation in work, education, or social activities. She highlighted how her service completed '*vocational assessments for other clients*' and queried why this is not similar for young men with DMD:

> '*so why not, like a vocational assessment for someone with DMD*…. A vocational assessment of some form whether that's the OT or an actual vocational assessor. *It's having a plan…. either TY or 5th year, you know looking at them at that age, going OK where do you want to go…. vocationally assessing or say educationally what are their needs, what are their interests, where they want to go?' (P17)*

6.3.1 Recommendations for Supporting Transition

Service providers identified that early and continuous preparation, starting in childhood, was essential for fostering independence, empowerment, and decision-making skills. They suggested that transition planning should be an ongoing process, rather than something addressed only at the last moment:

> *'that preparation work for independence, and I suppose empowerment, you know decision making needs to happen earlier in life and it's being built up as a skill throughout childhood rather than I suppose that kind of maybe more focused piece em before they transition.' (P18)*

All service providers emphasised the importance of a holistic approach in supporting the transition to adulthood, recognising that it should encompass more than just medical management. They highlighted the need for a '*holistic, rounded approach'* that extends beyond medical concerns, particularly as individuals with DMD are living longer:

> *'It's more than just a medical piece… It goes on too long, and everyone is living longer.'(P22)*

This perspective suggested that transition support should extend beyond clinical care to address thinking, emotions, behaviour, and how individuals engage with the world:

> '*the aim is to holistically look at thinking, feeling, behaviour, how you are in the world. It really gives you a space, it's like a platform, to start opening up where you think you could be and what spaces you want to occupy in the world'. (P23)*

Some service providers believed that a more social care-driven model would be more effective in transition planning, as medical services often prioritise urgent health concerns over broader life skills and personal development:

> *'it's never going to be valued if it's in the health sphere. I think other things will always trump it. I mean if you're in front of a surgeon, it's hard to get a surgeon's time and if have your 5 minutes then you're not going to talk about anything else.' (P22)*

A nationally developed transition programme, incorporating life skills training and interventions, was identified as beneficial for young men with DMD. One participant described her thoughts on such a programme:

> *'Life skills yeah, if that could be developed on a national level in the community by the CDNT I would absolutely back that 100%. Just to teach them the life skills of managing money, managing a PA, have confidence building workshops, life skills - you know how to fill out a housing application form…..but you know what I mean, just even develop those skills, I'd love it'. (P20)*

Service providers also recognised the value of a structured framework that would offer consistent and regular support throughout the transition to adulthood. Early preparation, starting around age 16, was seen as key:

> *'It would be good to have you know some form of a programme. I don't know it's, like that you would have I suppose like a process that you'll be checking in with them regularly.'(P16)*

All participants identified the age of 16 as an appropriate stage to begin transition planning. This is a time when discussion around transition between services begins to happen within current services:

> '*when the teenager is around 16 or thereabouts the conversation will start about the medical teams transition to services outside of the Children's Hospital*.' (P20)

A transition coordinator role was proposed to provide dedicated guidance and support '*over a 2–3-year period*' (P19), helping young men with DMD investigate options such as vocational programmes, day centres, and transport options:

> '*To help them while they're transitioning from school to a day centre or some sort of vocational programme. Someone to help them through what's, what's available in their areas, manage the transport.' (P19)*

This would emphasise goal setting, mental well-being, and active participation in adulthood. One participant believed that having *"a goal in mind"* could be *'good for their mental well-being as well'* (P19). Another highlighted that transition should go beyond simply meeting medical needs, recognising the importance of:

> *'Quality of life in relation to your participation, your engagement in activities.'*(P23)

Targeted support, specific to DMD, was also seen as important during transition to adulthood, not only to help the young men understand their condition but to promote a positive outlook and self-acceptance:

> *'And just to be proud of it. You know, I think people always say, doom and gloom about these things. I think people forget; you have to live as well. And which is very important.' (P16)*

A personalised approach was viewed by service providers as important to optimise the development of personal autonomy and decision-making skills and enabling opportunity to learn from experiences:

> *'These young boys have to make mistakes, they have to do things that are wrong, and they learn from it and move on…. it's all part of life and they should be allowed the same opportunities.' (P20)*

Service providers identified the value of a life skills programme as part of a broader transition initiative to support young men with DMD as they move into adulthood. Key interventions included fostering communication skills to help them advocate for themselves, promoting self-awareness and confidence in expressing their needs, and enabling independence through organisation and planning:

> *'it's about building that confidence…. and preparing them and helping them to advocate for their needs and giving them strategies' (P16)*

> *'I think that's what I'm saying about the social skills. That's part of the piece that I'm talking about, is actually that they can go in and speak for themselves and tell what they want not what a parent wants.'(P24)*

> *'Just talking about life skills… you know kind of planning, planning things, and having a voice of what their choices are.'(P22)*

Practical skills, such as managing money, navigating public transport, and coordinating personal care, were also identified as essential. Additionally, vocational assessments and support were recommended to help individuals explore opportunities beyond school, while

easily accessible information about community resources and educational pathways was considered vital.

> *'Just to teach them the life skills of managing money, managing a PA, have confidence building workshops, life skills - you know how to fill out a housing application form.' (P20)*

> *'vocational assessment of some form whether that's the OT or an actual vocational assessor.' (P17)*

> *'highlight what are the things that are available outside, what are the courses they could do,' (P16)*

Psychological support was another critical area, encompassing discussions around adulthood, relationships, and identity, as well as neuropsychological assessments to better understand how DMD affects cognitive function, emotional regulation, and daily living skills. Family support was also recognised as important in helping navigate changing roles during the transition to adulthood.

6.4 Conclusion

This chapter has presented the findings from the interviews with the service providers who participated in the study. The findings explored their perspectives on current service provision and their recommendations for improving support for young men with DMD as they transition to adulthood. Healthcare was perceived as prioritising physical management, with limited attention to psychological, social, and independence needs. Fragmented pathways, limited resources, and a lack of adult disability services left families without adequate support. Service providers recommended holistic, person-centred approaches, including dedicated teams, structured transition pathways, and life skills programmes. Collectively, they emphasised the need for coordinated and specialist supports to enable independence and quality of life during transition to adulthood.

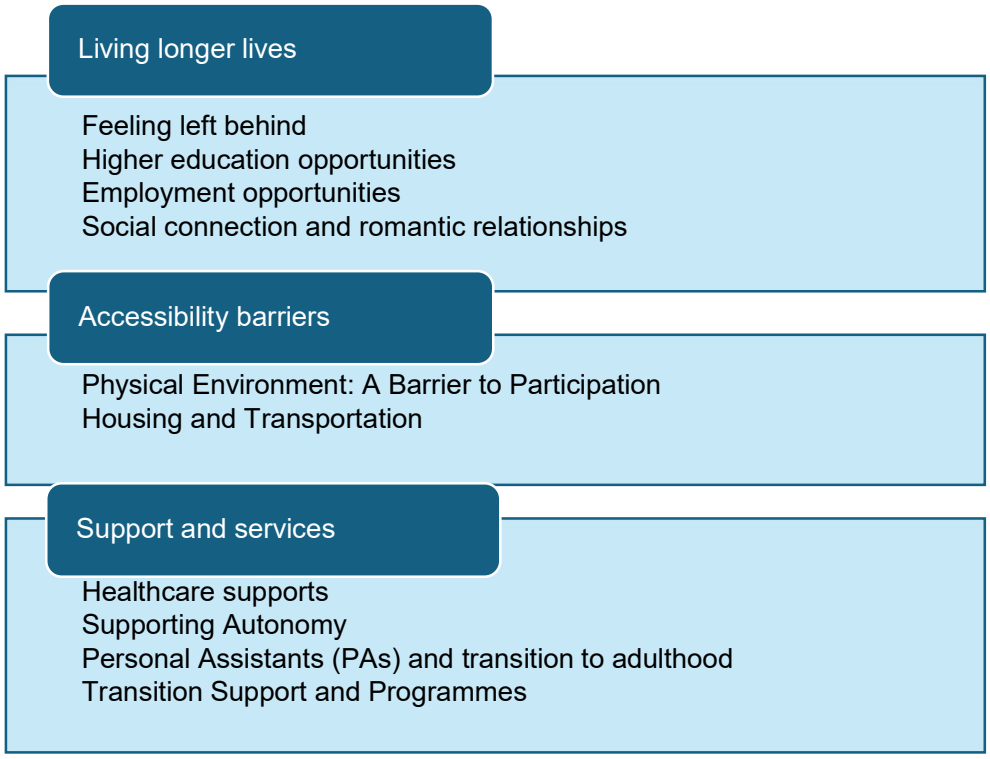
Chapter Seven, the final chapter of this thesis, will bring together the findings from all three participant groups: young men with DMD, parents of adolescents and young men with DMD, and service providers. They will be integrated and discussed within the context of the existing literature, while reflecting on the overall aims and objectives of the study.

7 Discussion

7.1 Introduction

The aim of this study was to explore the transition to adulthood for young men with Duchenne Muscular Dystrophy (DMD) from the perspectives of the individuals themselves, their parents, and service providers, while also identifying potential supports for this transition. The preceding three chapters have presented the findings of the study. Although the perspectives of the 3 groups were separated out, the transition to adulthood was common to all three chapters. In this chapter the findings from the three participant groups will be considered together in the context of the literature base and are discussed under the headings; Living longer lives; Accessibility barriers, and Support and Services. These are presented in Table 7-1. The findings from the young men and parent interviews are prominent across all three sections with the service provider interviews more represented in the third section.

Table 7-1: Discussion of findings in the context of current literature base



Following this discussion, the chapter presents recommendations across three domains—practice, policy, and research—before outlining the strengths and limitations of the study and concluding the chapter.

7.2 Living Longer Lives

Advancements in medical care, including respiratory and cardiac management, have significantly extended the life expectancy of individuals with DMD, shifting the focus from a childhood-centred condition to a lifelong, progressive disability (Landfeldt et al., 2020). Many individuals now live into their thirties and forties due to improvements in survival linked to multidisciplinary care (Landfeldt et al., 2020). However, while these medical advancements have allowed for a longer lifespan, they have also introduced new complexities regarding transition to adulthood, independence, and long-term planning (Donnelly et al., 2023). The findings of this study contribute to the growing body of research highlighting that, while medical advancements have extended the lifespan of individuals with DMD, corresponding improvements in home, community, and transition supports have not kept pace (Hoskin, 2020). Existing literature, relating to young people with impairments, indicated that while healthcare interventions have successfully prolonged life expectancy, social, vocational, and independent living supports remain underdeveloped (Stewart et al., 2014). This has left many young adults, including those with DMD and other disabilities, facing significant challenges in navigating adulthood (Donnelly et al., 2023; Stewart et al., 2014). The findings from this study reinforced these concerns. All participant groups highlighted that young men with DMD experienced a significant gap in support once they transitioned out of children's care. Many felt unprepared and without adequate guidance, facing challenges in navigating healthcare, personal assistance, and independent living arrangements on their own.

7.2.1 Feeling left behind

As young men with DMD transition into adulthood, increasing physical dependency can lead to feelings of being left behind, as their peers move forward into independent adult lives (Ee et al., 2023). The young men and parents who participated in this study echoed these experiences, describing how the progression of DMD increased reliance on family members and contributed to frustration and a sense of lost independence. While their peers typically experienced this life stage as a time of growing autonomy and self-

discovery (Arnett, 2007), young men with DMD often encountered a contrasting reality, marked by social isolation and limited engagement in typical adult milestones (Abbott & Carpenter, 2014). The young men who took part in the study described needing assistance to participate in educational and employment opportunities. They relied on parental support, while observing their peers gain more freedom to attend college, seek employment, and form new relationships. One participant described feeling "*stuck*" at home, watching his friends travel and enjoy new experiences as young adults. Parents also highlighted their ongoing caregiving role, which frequently extended into their sons' adulthood. Young men who participated expressed frustration as declining physical abilities restricted their capacity to manage everyday activities such as eating, dressing, and personal hygiene, diminishing their autonomy and control. These findings also align with Lindsay et al. (2016), who documented insufficient PA support and Donnelly et al. (2023), who identified broader gaps in structured transition services for young men with DMD and their families. In this study, some of the young men who participated expressed feeling unprepared and unsupported in navigating independent living or vocational pathways. Similarly, some parent participants echoed these concerns, sharing their frustration with insufficient transition planning and the lack of targeted services to promote autonomy for their sons.

7.2.2 Higher Education Opportunities

The transition to adulthood is often defined by milestones such as entering higher education, securing employment, and achieving financial independence. However, for young men living with DMD, these pathways are frequently hindered by accessibility barriers and limited vocational opportunities (Lindsay et al., 2016). For many young men participating in this study, higher education represented an opportunity to maintain routines and build social connections. They described pursuing higher education to maintain structure and a sense of purpose after finishing school. Their decision was influenced by social expectations and the desire to follow the same path as their peers, even if their long-term plans remained uncertain. One participant described how attending college felt like a natural next step, as it aligned with what his peers were doing. He also reflected on the positive social benefits, noting how meaningful it was to engage with others and be part of a social environment. Enrolling in further education provided continuity and a familiar routine while navigating the transition to adulthood.

However, barriers such as physical inaccessibility, fragmented transition planning, and insufficient support services frequently limit participation, placing young men with DMD at

risk of exclusion from further education, employment, and social activities (Castro et al., 2025; Lindsay et al., 2019). This was clearly reflected in the lived experiences of the young men who participated in this study. They described inaccessible campus environments and gaps in essential services, such as PA support. One young man described how despite arrangements being in place for PA support to help with essential tasks such as accessing bathroom facilities and navigating doorways he still hadn't received this support. He also highlighted environmental barriers on campus, including poorly designed and unsafe footpaths. These findings align with previous research suggesting that environmental barriers and fragmented support systems continue to place young people with DMD at risk of exclusion from further education and vocational activities (Lindsay et al., 2016). The Irish Wheelchair Association (2020) emphasises that best practice in accessible design should extend beyond minimum legal compliance to promote free and unimpeded access and use of all areas and functions within the built environment.

Parent participants described encountering barriers to higher education, including heavy fire doors, steep gradients, and poorly maintained footpaths that reduced their sons' independence and mobility on campus. Several parents also shared how their sons were unable to lift or turn the pages of physical textbooks and noted a lack of available information on accessible eBook alternatives within the settings. These concerns echo broader findings by Stewart et al. (2014), who noted that person–environment mismatches frequently undermine participation in key adult roles, including education, for young people with physical disabilities. Similarly, the Centre for Excellence in Universal Design (CEUD) promotes a universal design approach that anticipates the needs of all users from the outset. Its *Building for Everyone* guidance emphasises that environments should be planned and constructed so they can be accessed, used, and understood by people of all ages, sizes, and abilities (Centre for Excellence in Universal Design, n.d.).

In addition, participating parents identified insufficient PA support as a key barrier, noting that while PA or HCA services were technically available, finding reliable and adequately trained staff was difficult. Many reported that available assistants frequently lacked essential training in hoisting and were often unfamiliar with the specific care needs of young men with DMD. This is consistent with Castro et al. (2025), who noted that fragmented service delivery and the absence of condition-specific support undermine participation in higher education for this population. Additionally, one parent described the absence of structured transition planning for young men with DMD when his son first attended the college. In the absence of a tailored orientation programme, they were left to identify accessible toilets, lifts, and evacuation routes themselves. Service providers interviewed in this study further acknowledged that transition services often prioritised

physical health and equipment provision over vocational or educational goals. This reflects wider findings by Lindsay et al. (2019), who observed that transition services for young people with neuromuscular conditions frequently overlook social participation and independent living outcomes.

Although Ireland has inclusive education policies, such as the Disability Access Route to Education (DARE) scheme, parent participants in this study described mixed experiences when attempting to access support. Some parents described the DARE application process as poorly suited to the needs of young people with DMD. Some reported that their applications were rejected, while others found the process daunting and administratively burdensome. One young man missed out on college for a year due to complications associated with the scheme. A systematic review by Donnelly et al. (2023) highlighted that higher education can be one of the few relatively accessible pathways for young men with DMD, as traditional employment settings are frequently physically demanding and inaccessible. However, the review also highlighted the need for enhanced supports to ensure full participation, such as accessible course design, expanded PA funding, and greater awareness among faculty and peers regarding the needs of students with neuromuscular conditions.

In line with these findings, the Centre for Excellence in Universal Design (CEUD) advocates for inclusive educational environments that anticipate the needs of all learners, including those with physical disabilities. Its *Building for Everyone* guidance promotes flexibility in how learning is accessed, delivered, and assessed, emphasising that educational settings should be usable and understandable by all students, regardless of ability (Centre for Excellence in Universal Design, n.d.). Parents in this study identified a lack of accessible digital resources and assistive technology as significant barriers—issues that Universal Design principles explicitly address through a focus on inclusive, user-centred environments.

Organisations such as the Higher Education Authority (HEA) and AHEAD play a crucial role in supporting students with impairments in Irish higher education. According to AHEAD's report, students with disabilities who engage with support services in higher education experience a range of challenges, including accessibility barriers and the need for individualised accommodations (AHEAD, 2022). In Irish higher education, 7% of students have a disability, with those experiencing physical or mobility impairments comprising approximately 6–7% of this group (AHEAD, 2022). This means that students with physical impairment represent just 0.4–0.5% of the total student population, highlighting the need for enhanced policies and tailored supports to address their unique challenges (AHEAD, 2022). The AHEAD Strategic Plan (2024–2028) emphasises the

importance of amplifying the voices of students with disabilities, shaping national policies, and ensuring that inclusion is embedded across all levels of education and employment (AHEAD, 2024).

Ultimately, the capacity for young men with DMD to socially and academically thrive in higher education depends not just on “access” in its narrowest sense but on the ability to autonomously navigate, participate in, and shape the learning and social environments they are part of.

7.2.3 Employment Opportunities

There is currently no available data specific to employment outcomes for individuals with DMD in Ireland. However, existing national data indicates that employment rates for people with disabilities in Ireland remain disproportionately low, with only 36% of individuals with disabilities engaged in paid work compared to 72% of the general population (National Disability Authority (NDA), 2017). For those with physical impairments, additional barriers such as workplace inaccessibility, a lack of employer accommodations, and limited flexible job options further restrict meaningful employment opportunities (NDA, 2017).

These challenges are mirrored in research focusing specifically on young men with DMD, who face similar barriers to employment. Lindsay et al. (2016) identified persistent barriers to employment, including inaccessible work environments, limited access to vocational training, and gaps in tailored transition services. Similarly, Donnelly et al. (2023), in a systematic review of parental experiences, found that parents frequently reported environmental barriers and a lack of vocational opportunities as key factors limiting workforce participation for young men with DMD. Despite growing policy efforts to promote inclusive employment, Lindsay et al. (2016) emphasised that young people with DMD continue to encounter significant obstacles when attempting to access meaningful work.

Findings from the current study reinforced these concerns. At the time of participation two of the young men who took part were working. All the participating young men identified multiple challenges to work participation such as long commutes, difficulties accessing buildings, and inadequate transport options. Fatigue and the need for regular breaks to manage postural and care needs further complicated the prospect of full-time employment. Parent participants reported that many of their sons had shared their hopes of pursuing future work with them. However, most parents participating viewed employment as an unrealistic option due to significant accessibility barriers, transport challenges, and the lack of reliable PA support to enable participation in the workplace. Instead, many of these parents considered further education a more practical and sustainable pathway, describing

how they actively encouraged their sons to pursue additional courses in place of employment. Service provider participants also noted that structured vocational support was frequently absent from transition planning, with one clinician reporting that college or employment was rarely discussed within their clinical setting.

Most of the young men and the parents who participated in this study indicated that this lack of structured vocational planning meant that they were left to navigate college and employment opportunities on their own, often without the necessary supports or accommodations in place. Both young men and parent participants suggested that greater awareness of available supports could help improve opportunities for young men living with DMD. Both participant groups highlighted a gap in structured vocational planning which often left young men and their families without the accommodations or knowledge necessary to access meaningful employment opportunities.

Previous research has highlighted the importance of targeted employment schemes, employer education, and improved vocational and occupational services to address systemic barriers and promote workforce inclusion for young people with disabilities (Donnelly et al., 2023; Lindsay et al., 2019). Donnelly et al. (2023), in a systematic review of parental experiences, emphasised the importance of structured vocational supports and alternative employment models to address persistent barriers to employment for young men with DMD. Despite this, few studies have specifically examined vocational support frameworks for adolescents and young adults with DMD, highlighting a gap in both research and practice.

7.2.4 Social Connection and Romantic Relationships

Social connections, including friendships and romantic relationships, play a crucial role in the emotional well-being and quality of life of individuals with DMD and other physical impairments (Earle & Blackburn, 2020; Ee et al., 2023; Hoskin, 2020). However, research highlights that social isolation and limited engagement, often compounded by societal barriers, can negatively affect psychological well-being, while access to meaningful relationships and social participation is associated with improved mental health and life satisfaction (Earle & Blackburn, 2020; Ee et al., 2023; Hoskin, 2020). In this context, structured social participation and access to strong support networks play a key role in enhancing well-being and facilitating smoother transitions into adulthood (Earle & Blackburn, 2020; Stewart et al., 2014). Consequently, psychosocial support, including open discussions around relationships and intimacy, should form an integral part of healthcare and transition planning for young men with DMD (Earle & Blackburn, 2020; Ee et al., 2023).

Friendships provide a sense of belonging and social support, yet many young men with DMD experience social isolation, particularly after leaving structured environments such as school, as accessibility barriers and a lack of inclusive social opportunities contribute to reduced peer engagement (Ee et al., 2024; Lindsay et al., 2016; Hoskin, 2020). For many of the young men participating in this study the structured environment of school had provided a social framework, allowing them to form and maintain friendships. When leaving school there was a transition from regular engagement with familiar friends to a period of reduced social contact, which they described as challenging. One young man described his transition as a lonely experience. As his friends progressed into college, employment, or new relationships, his opportunities for social interaction declined, leaving him feeling increasingly isolated and aware that his peers had moved on with their lives. Parent participants also echoed this experience, reporting that their sons' friendships became increasingly distant after leaving school. One parent described how her son's online interactions with friends declined significantly as his friends moved on with their own lives, while another parent noted their son no longer had regular contact with friends who were now focused on employment and personal relationships.

This aligns with prior research indicating that young adults with disabilities face an increased risk of social isolation due to reduced participation in education, employment, and social activities (Stewart et al., 2001, 2014). In this study, some of the participating young men successfully transitioned into further education and formed new social connections, however most struggled to establish friendships within college or work settings. The young men described how reliance on wheelchair-accessible transport, the need for physical assistance with ADLs, and inaccessible social environments limited their ability to engage in activities outside structured commitments such as lectures. One young man who participated mentioned that social opportunities were rare due to inaccessible social venues and the fatigue associated with commuting. Parent participants similarly noted that their sons experienced growing isolation after leaving school as their friends moved on, while they remained dependent on family for companionship. This aligns with prior research indicating that young adults with disabilities often face increased social exclusion after leaving school due to reduced peer interaction, accessibility challenges, and limited institutional support for social integration (Stewart et al., 2014; Hoskin, 2020; Lindsay et al., 2016).

Romantic relationships are often overlooked in transition planning, leaving young adults with limited guidance on navigating intimacy and dating while managing a progressive condition (Earle & Blackburn, 2020; Hoskin et al., 2024). This study found no evidence of service-level supports aimed at helping young men develop romantic relationships,

friendships, or broader social connections as they transitioned into adulthood. Participating service providers acknowledged this gap, noting that psychosocial needs, including social relationships and intimacy, were often deprioritised in transition planning. Romantic relationships were an area of uncertainty for many young men participating in this study. Most participants had limited experience with dating, and some expressed little interest in actively pursuing romantic connections. Many felt that societal perceptions of people with disabilities created barriers to building relationships. One young man reflected that others frequently failed to recognise the emotional needs and romantic aspirations of young men like himself. Another participant shared feelings of self-doubt, believing that others would not see him as a potential romantic partner, and described distancing himself from romantic pursuits to avoid anticipated rejection.

Additionally, participating parents highlighted that their sons expressed concerns about dating and romantic relationships, sharing doubts such as, "*How would a girl like me?*" and expressing surprise when peers with similar conditions had romantic partners. Parents also recognised societal perceptions as a barrier, noting that others often focused on their sons as having physical disabilities, which limited opportunities to form new social connections. While research in this area remains limited, both Hoskin et al. (2024) and Earle & Blackburn (2020) acknowledge that young people with progressive or life-limiting impairments often encounter systemic barriers when it comes to romantic relationships and intimacy. Hoskin et al. (2024) further observed that while some young men with DMD have turned to online dating platforms to create social connections, these digital spaces can also pose challenges, such as difficulty forming meaningful interactions or sustaining conversations.

7.3 Accessibility Barriers

Access to essential services, personal care assistance and an accessible physical environment have been identified as important for transition to adulthood for young men with DMD (Lindsay et al., 2016). However, most participants in this study identified considerable barriers in these areas, impacting independence, education, employment, and social participation. These findings align with existing research, which highlights that despite medical advancements extending life expectancy, structural and policy-related obstacles, such as limited services, caregiving burdens, and financial strain, continue to restrict full societal participation for individuals with disabilities (Stewart et al., 2014; Lindsay et al., 2019; Landfeldt et al., 2016).

7.3.1 Physical Environment: A Barrier to Participation

Access to the built environment is essential for occupational engagement; however, young men with DMD encounter considerable barriers in public spaces, educational institutions, and social settings, including inaccessible environments and a lack of supportive accommodations (Lindsay et al., 2019). Despite policies promoting universal accessibility, many youths with disabilities, including those with DMD, continue to encounter barriers in public spaces and services, restricting full participation in community life (Stewart et al., 2014; Lindsay et al., 2019). The built environment continues to hinder independence, as inadequate architectural design often fails to accommodate wheelchair users, making essential facilities within the home, such bathrooms and entrances inaccessible (Lindsay et al., 2024). Barriers within the physical environment reinforce dependence on caregivers, limiting young men with DMD from engaging fully in adult roles and responsibilities, such as independent living, employment, and self-care (Barak et al., 2025).

Both the findings of the young men and the parent participant interviews identified numerous barriers in public spaces. One parent described how her son was unable to access a public bathroom and was forced to use an alternative space lacking privacy. Social spaces such as pubs and nightclubs remained largely inaccessible, restricting young men with DMD from participating in typical social activities. One young adult participant expressed his desire to socialise alongside his peers but frequently found himself unable to do so due to limited wheelchair access in these venues.

Although features such as lifts and automatic doors are designed to improve accessibility, their operation often assumes a level of physical ability that is inconsistent with the progressive upper limb weakness experienced in DMD. One parent described how her son was unable to press the lift button or select a floor without assistance. These experiences highlight a disconnect between standard accessibility features and the nuanced needs of users. Consistent with this, the Irish Wheelchair Association's *Best Practice Access Guidelines* (2020) emphasise that accessible environments should accommodate a broad spectrum of physical abilities through design choices that minimise physical effort and maximise usability.

Despite this, there is currently a lack of research specifically exploring how upper limb impairment impacts the ability of young men with DMD to navigate and participate in the built environment. This gap is reflected in real-life accounts. Within educational environments, two parents shared how their sons were unable to lift or turn the pages of

physical textbooks and noted a lack of available information on accessible eBook alternatives within the settings.

7.3.2 Housing and Transportation

At the time of participation in this study, all the young men and the sons of the parent participants were living in the family home and were reliant on parental support. Several of the young men expressed a desire to move out and live independently, and many parents described having conversations with their sons about the possibility of moving out of home in the future. Most of the young men noted, however, that a lack of accessible housing and personal support services made the prospect of moving out unachievable at the time. One young man remarked that he believed '*you should be able to move out'* (P1) and felt that he should be able to control his own life and not rely on parental support all the time. Parents described the scarcity of accessible housing options, giving the example that there were no '*bungalows being built anywhere'* (P14). These systemic gaps contributed to the challenges experienced by most young men when considering moving out of the family home (Barak et al., 2025; Donaldson et al., 2021). Some young men described how they remained in the family home while their peers moved on to university or employment opportunities.

Although the National Housing Strategy for People with Disabilities (2022–2027) outlines commitments to increasing accessible housing and supporting independent living, progress has been slow, with continued shortages preventing many individuals from transitioning into independent living (Department of Housing, Local Government and Heritage, 2022). These findings align with wider research, which shows that inadequate access to adapted housing limits young people's ability to transition into independent living (Barak et al., 2025; Donaldson et al., 2021; Lindsay et al., 2024).

Access to transport was essential for enabling participation for young men with DMD as they transitioned into adulthood (Lindsay et al., 2019; Stewart et al., 2001). However, the findings of this study revealed that transport-related barriers significantly affected participation in education, healthcare, and social activities, reinforcing dependence on parents. Several young men described challenges accessing public transport, such as being unable to board local buses or encountering inaccessible stations where ramps or lifts were unavailable. These unreliable and inaccessible options restricted their involvement in daily life. One participant explained how spontaneous social plans were often impossible, as he relied on pre-booked wheelchair-accessible taxis to accommodate his power wheelchair, limiting participation in outings with work or college peers and

reducing opportunities for social inclusion and autonomy. In addition to public transport barriers, both young men and parent participants identified a lack of opportunities to learn to drive independently. One participant noted that his attempts to learn to drive were hindered by the limited availability of adapted vehicles, with only one or two available nationally, which were frequently out of service.

These findings aligned with wider research. Barak et al. (2025) highlighted that transport accessibility was a significant barrier to social and vocational participation for young adults with DMD. Limited access to adapted transportation restricted independence and reduced opportunities in education, employment, and community participation (Barak et al., 2025; Donaldson et al., 2021). Similarly, Lindsay et al. (2019) found that transport barriers reinforced caregiver dependence, further limiting autonomy for young men with DMD. Addressing these challenges requires targeted policy interventions, including the expansion and reliability of accessible transport services and increased access to adapted driving programmes to foster greater independence during the transition to adulthood.

7.4 Support and Services

7.4.1 Healthcare supports

The transition from children to adult healthcare services is a complex and challenging process for young men living with DMD (Castro et al., 2025). While medical advancements have significantly extended life expectancy, healthcare systems have yet to fully adapt to the evolving needs of this adult population (Birnkrant et al., 2018b). The transition is frequently fragmented, with young men experiencing gaps in services, limited coordination between providers, and a lack of multidisciplinary adult care teams (Castro et al., 2025). Both young men and parent participants described having to navigate the transition between services largely on their own, often without structured guidance or support from healthcare providers.

Service provider participants highlighted that children's hospital healthcare services for DMD are typically delivered through multidisciplinary, consultant-led teams, including neurologists, respiratory specialists, occupational therapists (OTs), physiotherapists, and social workers. These services were regarded as comprehensive and coordinated. In contrast, adult services were perceived as fragmented, under-resourced, and lacking equivalent structures to address the complex and progressive nature of DMD. Community-based teams, such as the Children's Disability Network Teams (CDNTs), provided generalised support but were often perceived to lack specialist knowledge of DMD. Parent

participants echoed these concerns, describing the lack of clear pathways from children to adult care and reporting gaps in post-transition services, such as reduced access to physiotherapy and occupational therapy. Some parents felt unsupported by services and found the responsibility of navigating adult services challenging. The young men who participated similarly highlighted the contrast between the structured, multidisciplinary children services and the fragmented adult care they encountered. They described difficulties navigating adult services, including challenges accessing therapy and essential equipment reviews.

Findings from the service providers also identified that adult primary care services did not provide a multidisciplinary or disability-specific model of care. Service providers reported that adult teams primarily focused on equipment provision, rather than addressing the holistic needs of individuals with DMD. This finding aligns with broader research which shows that, despite increased survival rates, healthcare systems frequently fail to deliver the same standard of coordinated, multidisciplinary care to adults with DMD as is available during childhood. (Birnkrant et al., 2018c; Castro et al., 2025). In contrast, well-integrated transition programmes implemented in countries such as Denmark demonstrate improved health outcomes, greater independence, and enhanced psychological well-being for individuals with neuromuscular conditions (Hoskin, 2020). Coordinated multidisciplinary teams that extend into early adulthood, ensure that individuals continue receiving comprehensive care beyond children services (Hoskin, 2020).

Service provider participants and existing literature identified that healthcare services for young men with DMD often prioritise physical health management while neglecting psychosocial, emotional, and mental health support (Hoskin, 2020). Service provider participants acknowledged that intervention and support typically focused on monitoring physical function and ensuring that adaptive equipment met postural and functional needs. This focus on physical health was prioritised over broader psychosocial needs. Mental health and emotional supports were described by service providers as notably absent, despite the young men participating in the study expressing a need for support during their transition to adulthood. Service providers perceived that the progressive nature of DMD contributed to increased anxiety, and some young men in the study identified that they would like support relating to the uncertainty about their future, yet these needs were rarely addressed in clinical settings. These concerns align with the findings of Hoskin (2020), who argues that psychological well-being, emotional adjustment, and social participation are important components of a successful transition to adulthood. Additionally, research suggests that integrating peer mentoring, psychosocial supports, and structured self-advocacy training into healthcare services can foster confidence and resilience, while

reducing social isolation and promoting long-term well-being among young people with disabilities, including those with DMD (Hoskin, 2020; Lindsay et al., 2019). Alongside these healthcare service challenges, young men with DMD and their families face important decisions about autonomy, independence, and the role of structured support during the transition to adulthood.

7.4.2 Supporting Autonomy

Both Stewart (2001) and Hoskin (2020) discuss the need to redefine independence for young people with physical impairments, shifting away from traditional concepts of self-sufficiency to a more interdependent approach that recognises the importance of environmental supports, decision-making opportunities, and structured transition services. Traditionally, adulthood has been measured by milestones such as independent living, employment, and financial self-reliance (Côté & Bynner, 2008). However, for young men with progressive disabilities like DMD, these conventional benchmarks often require adaptation or become unattainable due to the physical, medical, and social barriers they face (Ee et al., 2024; Castro et al., 2025; Lindsay et al., 2019).

Research suggests that for young men with DMD, independence should be reframed as the ability to self-direct and make choices within a system of coordinated support (Hoskin, 2020). Broader research on young people with physical disabilities similarly highlights the importance of redefining independence within supportive networks (Stewart et al., 2009). Stewart (2009) highlights that receiving assistance does not diminish autonomy; rather, when well-structured, it can enhance self-determination and enable fuller participation in society. She advocates for a life course approach to transition planning, where autonomy is fostered through interdependent networks that support young adults to engage meaningfully in adult roles, instead of placing them in systems that assume full self-sufficiency as the norm. Similarly, Hoskin (2020), drawing on Priestley's (2003) concept of "independent dependence," explores how young men with DMD can achieve independent living while continuing to rely on full-time personal assistance or other external supports to manage daily activities, maintain social participation, and navigate adult life.

This evolving understanding of autonomy was reflected across interviews with young men, parent, and service provider participants, all of whom highlighted the importance of balancing autonomy with structured support during the transition to adulthood. The young men described their desire for independence and self-direction, with some expressing a wish to live independently, most pursuing further education and seeking engagement in a

social life, yet they all acknowledged their reliance on others for personal care and assistance (e.g., toileting, mobility, and daily tasks) which they found both necessary and, at times, frustrating. Parents were perceived by all participant groups as playing a dual role: providing physical assistance while fostering their sons' capacity for self-advocacy. Some parent participants found it difficult to step back, inadvertently limiting opportunities for young men to take control of decision-making, particularly in healthcare contexts where young people were sometimes seen as passive participants by the service provider participants. While several parents described how they actively encouraged their sons to articulate their needs and preferences, others struggled to relinquish control, delaying the development of self-advocacy skills. These findings align with Lindsay et al. (2019), who emphasise the importance of structured coaching and self-advocacy training to enhance transition outcomes. This complements the broader work of Stewart (2009) and Hoskin (2020), who stress the need for balancing autonomy with supportive networks during the transition to adulthood.

7.4.3 Personal Assistants (PAs) and transition to adulthood

For young men with DMD, personal assistants (PAs) are vital in facilitating participation in daily life and enabling autonomy, particularly as their physical dependence increases (Lindsay et al., 2016). While many young men with DMD aspire to live independently, pursue further education, and engage socially, they often rely on PAs to assist with essential activities of daily living such as mobility, self-care, and accessing the community (Lindsay et al., 2019). The presence of consistent and reliable PA support is critical in overcoming the physical and environmental barriers these young men encounter, allowing them to maintain autonomy and engage in meaningful occupations despite the progressive nature of their condition (Lindsay et al., 2019).

"Achieving a Right to Personal Assistance in Ireland" (Independent Living Movement Ireland [ILMI], 2019) supports the claim that PAs play a critical role in enabling independent living for people with disabilities in Ireland. It states that PAs provide individualised support that goes beyond personal care, facilitating social inclusion, education, employment, and community participation. Unlike Healthcare Assistants (HCAs), who operate under a structured healthcare framework, PAs work under the direct instruction of the person receiving assistance, ensuring that individuals retain maximum autonomy and control over their daily lives (ILMI, 2019). In Ireland, PA services are not guaranteed by law, leading to inconsistent access that depends on regional funding and eligibility criteria (ILMI, 2019). Unlike countries where PA services are a statutory right, Ireland's discretionary funding

model creates uncertainty for service users, with many receiving insufficient PA hours to support full participation in education, employment, and community life. As a result, many people with disabilities remain dependent on family caregivers or institutional care, limiting autonomy and independent living (ILMI, 2019). Other research has also highlighted that access to reliable PA support remains inconsistent, with challenges in funding, recruitment, and retention leading to disruptions in care, particularly in countries where PA services are not a statutory right (Hoskin, 2020). In contrast, in Denmark, where PA services are a statutory right, young men with DMD reported greater autonomy and security, supported by consistent access to 24-hour personal assistance. This model enabled them to live independently, maintain social participation, and engage more fully in adult roles (Hoskin, 2020).

The results from this study highlighted that many of the young men who participated would like to live independently but cannot do so without reliable and consistent PA support. One participant noted that despite his desire to move out, he remains at home because he lacks sufficient assistance to support his self-care and mobility needs. While PAs are essential for maximising independence, findings from young men, parents and service providers reveal considerable challenges in accessing, recruiting, and retaining reliable PA support. When the young men had access to a PA, they described experiences of high turnover rates where one young man reported experiencing four different PAs within a short time frame.

Service providers emphasised that supporting young men with DMD to manage and coordinate PAs was an important step in supporting their transition to adulthood. They highlighted that developing key skills in communication, planning and organisation can support young men to navigate independent living with greater confidence. Service providers perceived that by communicating their needs, preferences, and expectations to PAs, young men can take an active role in directing their care, rather than relying on family members or professionals to make decisions on their behalf. Service providers also stressed that providing young men with skills to organise their schedules and coordinate PA support would foster greater autonomy and control over personal decision-making.

Without systemic improvements in PA provision and disability supports, young men with DMD will continue to face considerable barriers to autonomy and meaningful participation, limiting their ability to transition into adulthood successfully. Limited access to structured PA services and inadequate transition supports hinder opportunities for education, employment, and community participation, forcing many individuals to rely heavily on family caregivers (Hoskin, 2020; Lindsay et al., 2019). The lack of home and community-based supports left young men with DMD dependent on informal care networks, restricting

their ability to engage in independent decision-making and self-directed living (Hoskin, 2020).

7.4.4 Transition Support and Programmes

Findings from this study identified that all participant groups perceived a lack of tailored transition supports available to adolescents and young men with DMD. Parent participants described how as their sons moved towards adulthood, they became increasingly reliant on parent and family support, not solely because of changing functional abilities but due to the absence of structured services, including PA provision. Parents also voiced frustration over the limited vocational and employment support available, noting their sons struggled to access vocational training or find workplaces equipped to meet their physical needs. The absence of adequate support impacted their sons' opportunities for engagement in meaningful employment and reinforced long-term dependence on parents and family. These findings are echoed in Donnelly et al. (2023), where parents reported inadequate transition supports and highlighted the emotional and physical burden of filling systemic gaps, particularly during the transition to adulthood. This review found that parents frequently needed to advocate for their sons due to a lack of professional understanding of DMD and expressed concern over limited access to PAs, vocational supports, and employment accommodations, which exacerbated long-term reliance on family caregiving.

This was mirrored by the findings from the young men, who expressed feeling unprepared for adulthood with most describing feelings of uncertainty and a lack of structured support. An issue identified by some young men in this study was the absence of long-term life planning, as doctors and therapists often avoided discussions about the future. One young man speculated that this reluctance stemmed from the life-limiting nature of the condition. Previous research has similarly found that some young men believed healthcare professionals were hesitant to discuss long-term prospects, contributing to feelings of uncertainty about adulthood (Abbott & Carpenter, 2014). It has been suggested that this reluctance is linked to the progressive nature of DMD, causing professionals to prioritise immediate medical needs over long-term planning, ultimately leaving young men unprepared for their future (Ee et al., 2023). Many described the transition between child and adult healthcare as disjointed and lacking a clear pathway. Some reported frustration at the reduced contact with key allied health professionals like physiotherapists and occupational therapists, which resulted in delays in accessing essential equipment such as wheelchairs. Some young men shared that they felt unsupported, experiencing a lack

of direction, with no formal supports or educational programmes to guide them through this period. They described being left to figure things out themselves perceiving a lack of guidance around finding suitable employment and securing PA support to meet their needs. This impacted their opportunities for engagement in further education, employment and social activities. One young man expressed that better access to PA support would enable greater independence, stating he needs full-time assistance to go anywhere on his own. Insufficient transition planning and limited referrals to vocational and occupational services often contribute to young people with neuromuscular disorders, such as DMD, facing increased risks of unemployment, social isolation, and prolonged dependence on their families due to a lack of essential supports and resources (Lindsay et al., 2019).

Both service provider and parent participants described that the transition support within CDNTs was broad and generalised, rather than tailored to the specific needs of adolescent's with DMD. Services were described by service providers as designed to accommodate a wide range of needs, including Autism, Intellectual Disability, and various physical impairments, rather than addressing the unique and progressive challenges associated with DMD. Many of the parent and service provider participants perceived that adolescents and young men with DMD often received generic transition support that failed to consider their medical, social, and psychological needs associated with a progressive condition. Service providers also identified gaps in communication between children and adult services, noting that fragmented service delivery created additional challenges for young people and their families during the transition to adulthood. These concerns are consistent with wider research, which highlights that transition planning for young men with DMD is often inconsistent, lacks condition-specific supports, and frequently results in poor adult service outcomes (Castro et al., 2025; Lindsay et al., 2019). Lindsay et al. (2019) also emphasises that without tailored transition pathways, including supports for education, employment, and life skills, young people with neuromuscular conditions are left without viable routes into adult roles.

7.5 Recommendations of the Study

The findings from this study highlight the need for more coordinated, person-centred approaches to transition planning for young men with DMD. The recommendations are presented under three key domains: practice, policy, and research.

7.5.1 Recommendations for Practice

- This study recommends the implementation of targeted skills development initiatives to promote self-advocacy, life skills, and independent living among young men with DMD. These initiatives should create opportunities for peer mentoring and peer support networks, fostering confidence and reducing social isolation. In addition, transition services should fully integrate psychological and psychosocial supports, including access to mental health counselling and peer-led groups, to address the emotional and social challenges highlighted by participants.
- At a service level, this study recommends the development of specialist Adult and Young Adult Multidisciplinary Teams (MDTs), modelled on existing CDNTs, to improve communication and coordination between children and adult services. Both young men and parents reported significant challenges navigating fragmented services, which often resulted in delayed access to essential supports. Also recommended is the appointment of dedicated transition coordinators with specialist knowledge of DMD. These coordinators would streamline service delivery, strengthen links between healthcare providers, vocational services, and community supports, and ensure a more cohesive, person-centred transition process for young men and their families.
- To better support families, this study recommends the development of family-focused support programmes to assist parents in managing their ongoing caregiving roles. Such programmes should also include coaching on promoting independence and self-determination among their sons. Young people and their families would benefit from the creation of a centralised, easily accessible digital platform providing up-to-date information on available healthcare, vocational, social, and housing supports.
- To enhance the quality of transition support, this study recommends that clinicians across all relevant services receive specialist training on the specific needs of young men with DMD, including the progression of the condition and its impact on adult life. Training should also equip professionals with the confidence to address sensitive topics, such as life-limiting conditions, future planning, romantic relationships, and psychosocial well-being. These developments would ensure that transition planning is holistic, individualised, and responsive to the broader medical, emotional, and social needs of young men with DMD.

7.5.2 Recommendations for Policy

- This study recommends the introduction of a national Personal Assistance (PA) policy to guarantee timely, equitable, and flexible access to PA services for young adults with progressive impairments such as DMD. The policy should ensure that PA supports are universally available, user-directed, and tailored to the individual's personal, medical, and social needs. PAs should be available to facilitate participation in education, employment, and community life, with minimum service standards and specific guidance on required skillsets, including hoisting and specialist care. In addition, mandatory PA funding should be linked to educational, vocational, and social engagement to ensure that young adults with DMD can optimise participation in all areas of daily life.
- To reduce environmental barriers, this study recommends that national policy mandates the implementation of Universal Design principles across all public buildings, educational institutions, workplaces, and community spaces. Enhanced accessibility standards should include level-access entrances, automatic doors, accessible parking, and fully equipped accessible bathroom facilities with hoisting equipment. Higher education institutions and workplaces should be required to meet these enhanced criteria to ensure full inclusion.
- This study recommends that national policy prioritise the expansion of both accessible housing and transport infrastructure to promote independent living for young adults with DMD. Accelerating the implementation of the National Housing Strategy for People with Disabilities (2022–2027) is essential, with a focus on increasing the availability of accessible housing options, including adaptations such as hoisting facilities and step-free layouts. In parallel, national accessible transport schemes should be expanded to include the reintroduction of adapted driving lesson programmes and the development of flexible transport subsidies. These initiatives would help address concerns raised by young men and parents in this study, who reported that environmental and transport barriers restricted participation in education, employment, and social life, leading to a continued reliance on family.
- It is recommended that specialist Adult and Young Adult Multidisciplinary Teams (MDTs), including dedicated transition coordinators, be formalised within the Sláintecare Implementation Strategy and national disability inclusion frameworks, to enhance communication and coordination of services across children and adult healthcare and disability sectors. National clinical guidelines should require that transition planning includes training for healthcare providers on addressing

psychosocial issues, including sensitive topics such as intimacy, romantic relationships, and mental health. This would help ensure that services adopt a more holistic and person-centred approach in line with contemporary best practice.

- National transition planning frameworks should mandate that all young people with progressive impairments, such as DMD, have access to tailored, person-centred transition programmes. These programmes should be supported by ring-fenced funding to ensure delivery within children's disability services, educational institutions, and community organisations. This study recommends that national policy prioritise the expansion of inclusive community and vocational programmes for young people with progressive impairments. This includes increasing investment in supported employment initiatives, career guidance services, and accessible further education pathways tailored to the specific challenges faced by young men with DMD.

7.5.3 Recommendations for Research

Future research should focus on addressing gaps identified in this study, with an emphasis on developing and evaluating targeted interventions to support young men with DMD during their transition to adulthood. Future research could:

- Investigate the development and evaluation of a structured, co-designed transition programme for adolescents with DMD, shaped by their lived experiences and addressing healthcare management, vocational planning, independent living, social participation, and psychosocial well-being.
- Investigate the effectiveness of co-designed life skills programmes in promoting independent living and social participation.
- Conduct longitudinal research to assess the impact of structured transition programmes on autonomy, quality of life, and community participation in young men with DMD.
- Examine how healthcare providers address psychosocial topics such as relationships, sexuality, and social inclusion in clinical settings.

7.6 Strengths and Limitations

The strengths and limitations of this study are outlined below.

7.6.1 Strengths

A key strength of this study is its inclusion of multiple perspectives, offering a broader understanding of the transition to adulthood within the Irish context. Young men with DMD shared their lived experiences, while parents and service providers provided their perspectives on the transition process and existing service supports. This provided valuable insights into how transition could be supported in the future.

The study employed a qualitative descriptive methodology, which is well-suited to capturing rich, detailed accounts of lived experience. This approach ensured that participant voices were represented, making the findings accessible and directly relevant to healthcare and disability support services.

Braun and Clarke's reflexive thematic analysis (RTA) was used to guide data analysis. This method highlights the researcher's active role in knowledge production, treating subjectivity as a resource rather than a limitation. Reflexivity is central to RTA, requiring the researcher to critically examine their own influence on data interpretation (Braun & Clarke, 2019).

7.6.2 Limitations

Recruitment for this study was challenging. DMD is a rare, life-limiting condition, with only 48 young men aged 18 and older currently registered with Muscular Dystrophy Ireland (MDI). This was the sole source of information available, as no centralised database exists. Consequently, participant recruitment was limited to a small pool of individuals who met the inclusion criteria.

Although ethical approval was obtained for both focus groups and individual interviews, engagement across both formats proved difficult. Due to the timing of recruitment and logistical considerations, only interviews were completed. This decision ensured that participants could engage with the research flexibly and in a way that accommodated their health, caregiving responsibilities, and service provider schedules.

Nonetheless, the sample size is consistent with other qualitative studies on DMD. For example, Lindsay et al. (2019) recruited 8 young adults with DMD and other neuromuscular disorders, alongside 11 parents and 7 practitioners. Similarly, Earle et al. (2023) focused exclusively on the lived experiences of young men with DMD, recruiting 5 participants in a palliative care setting. In this study, 8 young men with DMD, 7 parents,

and 9 service providers participated, placing it within the range of comparable qualitative research (e.g., Earle et al., 2023; Lindsay et al., 2019).

Within the service provider group, there was an overrepresentation of occupational therapists (OTs), with only one support worker participating despite extensive recruitment efforts. This limits the breadth of perspectives within the service provider subgroup. While the sample size was modest, it is consistent with Braun and Clarke's (2016) assertion that qualitative research should prioritise data richness over numerical thresholds. The study's findings are not intended to be generalisable but offer valuable insights into the experiences of the DMD community in Ireland.

The researcher's clinical background in DMD care was an asset in shaping the study but also carried the potential for bias. This was addressed through reflexive strategies, including journaling and supervision discussions. In addition, thematic analysis, which inherently involves researcher interpretation, was strengthened through collaborative coding and cross-checking with the research supervisor to enhance analytical rigour.

Although member checking provides an opportunity to enhance the credibility of qualitative findings through participant validation, it was not undertaken in this study. This decision is in line with Braun and Clarke's reflexive thematic analysis, which views themes as the researcher's interpretation of the data, rather than facts that need to be confirmed by participants (Braun & Clarke, 2019, 2021). While including participant feedback might have added another layer of understanding, not using member checking does not reduce the value of the findings. The themes represent patterns found across all interviews, not the views of any one individual.

The research was completed as a Masters study and thus the researcher was new to qualitative research and research interviewing. However, as an Occupational Therapist the researcher has considerable experience in interviewing both parents and young people and in communicating with service providers. The research supervisor has considerable experience in qualitative research and provided guidance across all stages of the research process.

7.7 Conclusion

This chapter has drawn together the perspectives of young men with DMD, their parents, and service providers to explore the complexities surrounding the transition to adulthood in Ireland. The findings highlight that while advances in medical care have extended life expectancy, the social, vocational, and structural supports necessary for meaningful adult

participation have not kept pace. Young men with DMD continue to face significant barriers related to accessible environments, fragmented healthcare and social services, and inconsistent access to essential supports such as personal assistants and vocational programmes. These challenges reinforce reliance on parents and restrict opportunities for independent living, education, employment, and social participation.

Additionally, the study illustrates that autonomy for young men with DMD must be understood as interdependent, requiring the coordinated efforts of families, healthcare providers, and community services. Despite national and international commitments to improving transition pathways, gaps persist, particularly in the provision of tailored supports and the prioritisation of psychosocial well-being within transition planning.

The findings highlight the need for systemic reforms, including coordinated multidisciplinary services, expanded personal assistance provision, and the integration of psychosocial and vocational supports. The recommendations provided in this chapter offer clear directions for practice, policy, and research, aiming to enhance the transition experience and improve outcomes for young men living with DMD in Ireland.

This chapter has concluded this research by discussing the research findings in depth, and providing recommendations for policy and practice, for future research and finally, highlighting the research's strengths and limitations.

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9 Appendices

Appendix 1: Literature Review Search Strategy

Duchenne Muscular Dystrophy and their transition to adulthood.

Copy/paste each line below into the search box in EMBASE. You need to also copy/paste those lines with numbers. I have indicated how many articles each search will find. You sort by relevance to see the most relevant articles (as in image below).

EMBASE (189)

'Duchenne muscular dystrophy'/exp

('Duchenne muscular dystrophy' OR 'duchenne syndrome' OR 'duchenne type muscular dystrophy'):ti,ab,kw

#1 OR #2

'transition to adult care'/exp OR 'adulthood'/exp

((Transition* OR becom* OR experienc* OR negotiat*) NEAR/3 adult*):ti,ab,kw

('child* to adult*' OR 'teen* to adult*'):ti,ab,kw

'employment'/exp

Employ*:ti,ab,kw

((work* OR school OR university OR educat*) NEAR/3 (opportunit* OR participat* OR access*)):ti,ab,kw

#4 OR #5 OR #6 OR #7 OR #8 OR #9

#3 AND #10

Medline (90)

Muscular Dystrophy, Duchenne/

(Duchenne muscular dystrophy OR duchenne syndrome OR duchenne type muscular dystrophy).tw.

1 OR 2

Transitional Care/ OR Transition to Adult Care/

((Transition* OR becom* OR experienc* OR negotiat*) adj3 adult*).tw.

("child* to adult*" OR "teen* to adult*").tw.

exp Employment/

Employ*.tw.

((work* OR school OR university OR educat*) adj3 (opportunit* OR participat* OR access*)).tw.

4 OR 5 OR 6 OR 7 OR 8

3 AND 9

CINAHL (79)

(MH "Muscular Dystrophy, Duchenne")

TI ("Duchenne muscular dystrophy" OR "duchenne syndrome" OR "duchenne type muscular dystrophy") OR AB ("Duchenne muscular dystrophy" OR "duchenne syndrome" OR "duchenne type muscular dystrophy")

S1 OR S2

(MH "Transition to Adulthood") OR (MH "Transitional Care") OR (MH "Transitional Programs")

TI ("transition to adult care" OR adulthood OR ((Transition* OR becom* OR experienc* OR negotiat*) NEAR/3 adult*) OR "child* to adult*" OR "teen* to adult*" OR Employ* OR ((work* OR school OR university OR educat*) NEAR/3 (opportunit* OR participat* OR access*))) OR AB ("transition to adult care" OR adulthood OR ((Transition* OR becom* OR experienc* OR negotiat*) NEAR/3 adult*) OR "child* to adult*" OR "teen* to adult*" OR Employ* OR ((work* OR school OR university OR educat*) NEAR/3 (opportunit* OR participat* OR access*)))

S4 OR S5

S3 AND S6

Web of Science Core Collection (413) - Topic Search as in image below

("Duchenne muscular dystrophy" OR "duchenne syndrome" OR "duchenne type muscular dystrophy") AND ("transition to adult care" OR adulthood OR ((Transition* OR becom* OR experienc* OR negotiat*) NEAR/3 adult*) OR "child* to adult*" OR "teen* to adult*" OR Employ* OR ((work* OR school OR university OR educat*) NEAR/3 (opportunit* OR participat* OR access*)))

Google Scholar

"Duchenne muscular dystrophy"
"Transition|transitioning|transited|becoming|experience||experienced|experiences|negotiate| negotiating AROUND(3) adult|adulthood"

"Duchenne muscular dystrophy" "child|childhood|teen|teenager|puberty to adult|adulthood"

Appendix 2: Ethics Approval for young men

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Dr Michelle Spirtos,
Discipline of Occupational Therapy,
Trinity Centre for Health Sciences,
James Street,
Dublin 8

21st June 2023

Ref: 220612
Title of Study: Supporting Transitions to Adulthood Resources (STAR) Project

Dear Michelle,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in June 2023, we are pleased to inform you that the above project (as amended with the following changes) has ethical approval to proceed. Your approval is pending subject to approval of your local DPO.

Please give specific details of the requested amendment(s):
Change the age band from 21 years to 20 years to over 18 years (all persons 18 and over)

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

Jacintha O'Sullivan

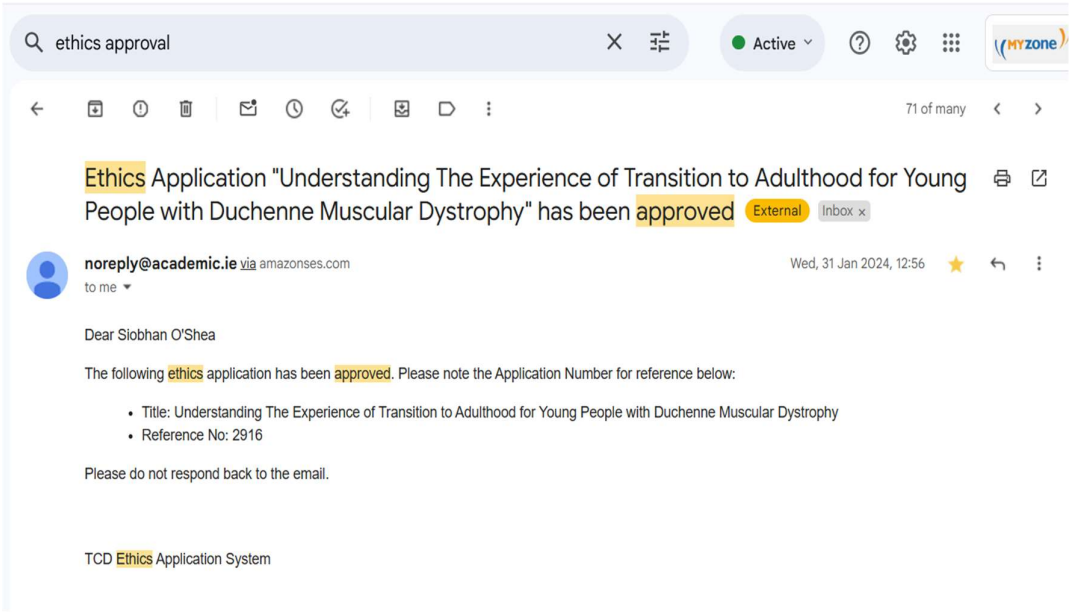
Prof. Jacintha O'Sullivan
Chairperson Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte
Foirgneamh na Ceimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

Appendix 3: Ethics Approval for parents and service providers



Appendix 4: Data Protection Impact Assessment Approval

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Date:14th March 2024

From: RDPO, Secretary's Office

To Dr. Spiritos, and Siobhan O Shea

Re: Record of review of DPIA

Dear Siobhan and Michelle,
Please find attached your Data Protection Impact Assessment (DPIA) for the project entitled' Understanding the Experience of Transition to Adulthood for young people with Duchenne Muscular Dystrophy
reviewed by the DPO's office on the following dates:

Name	Date	Reviewed/Consulted
Imelda O'Keeffe	15.12.2023	*Reviewed DPIA, PIL, ICF*
DPO Details : Evelyn Fox, RDPO	01. 03. 24	*Reviewed DPIA V1 and PIL and ICF V.2 (V.1 of PIL and ICF reviewed on 26. 01. 24)* *No key being kept between individual and their transcript so following verification (2 weeks) information is pseudonymised but with no link being kept back to the individual's identity. I therefore advice secure deletion of consent forms at that stage. Otherwise you risk re-identification.*
Evelyn Fox .	14. 03. 24	Updated DPIA V.2 to provide record of review.

I am satisfied that my advice has been taken into account in the completion of this DPIA, as is required by Article 35 (3) of the General Data Protection Regulation (EU) 2016/679 (GDPR).

Please note that the completion of a DPIA is not a one-time exercise, but a continual process. If there is any change to the processing envisaged by this DPIA, please contact me.

Please note that the DPO's unit are also entitled to carry out a review to assess if the processing is performed in accordance with this DPIA.

The best of luck with your research.

All the best,
Evelyn Fox, Solicitor
Research DPO
Secretary's Office

Appendix 5: Interview Guide – Young Men

INTERVIEW QUESTIONS

Welcome and thank you for agreeing to participate in this interview.

I am interested to hear your personal experiences of growing up and preparing for adult life. I'd like to hear what challenges you may have encountered and any ideas you may have of things that helped you or would help other young people and their families prepare for this time.

You can talk about your own experience or in general about what your thoughts are on these experiences for anyone with Duchenne Muscular Dystrophy. If you have any personal stories you would like to share, I would love to hear them, or if you know of experiences in general that you might like to share that would be great also.

Not all questions may be relevant and that is no problem, these are guiding questions where you only need to answer what is applicable for you.

At any time, you can take a break or chose to stop the interview.

Part 1

Can you tell me a little about your life now, what you are doing, what you are interested in, anything that occurs to you (where you are living/working?)

Can you give me an example of things you like doing.

Can you tell me what was happening around the time you were preparing to leave school, how were decisions being made, how did you decide what you wanted to do next.

Can you tell me about any help or support you found useful at this time.

Can you describe what it felt like for you when you were planning to leave school. (nervous,anxious,excited,happy…..)

What kind of challenges did you face at this time, have you any examples you can describe or share with me.

How do you think having DMD impacted or influenced your experience

Reflecting back now what do you think might be helpful for other young people preparing to leave school, what type of supports could be helpful

Can you tell me about life after school, describe what you have been doing between then and now.

Can you describe any particular challenges you have faced since leaving school.

What impact did DMD have on your experience at this time, can you share an example?

Would you say living with DMD meant you encountered more challenges than other young people of the same age, can you describe a situation for me?

Starting college – what was this like for you?

How did you prepare for this?

Can you tell me about supports you found helpful at this time?

What impact did DMD have on your experience, what challenges or barriers do people with DMD face when considering college?

Part 2

How would you describe your social life since leaving school?

What impact does living with DMD have on how you socialise?

How do you think it is in general for young people with DMD socialising with their peers in the years after leaving school?

Would you say having DMD influence your choice of social activities, can you give me an example or describe a situation.

Do you think social media/social network opportunities influence how you socialise? Can you give me an example?

Can you tell me a little about your friendships and who you like to socialise with?

How might it feel for a person with DMD to be the only one in a social group with a disability?

Do you feel comfortable talking about DMD with people you may not know very well?

Is it important to feel prepared for these social interactions?

What might help someone feel prepared?

Can you tell me what it's like for young people with DMD meeting new people for the first time?

Have you any examples of how someone might feel in this situation, would they generally feel prepared to answer questions people ask

Are there strategies or things that made or would make these experiences easier?

Thinking of personal or romantic relationships, can you describe what this might be like for a young person with DMD.

Do you have any examples of relationships you know about that you can share?

What are the challenges faced by young people with DMD in both forming and maintaining personal relationships?

Can you think of any useful strategies or supports that would help in these situations

WORK – What are your thoughts about working.

How did you decide on your career choice or if you wanted to work?

How did DMD influence or factor into your decisions – have you an example?

Does DMD impact on how young people living with the condition think or view work – How does it?

What are the barriers for young people with DMD when considering jobs, employment?

What did you find helpful in terms of supports when working?

What supports would you like to see for young people with DMD seeking employment?

When applying for a job or attending interviews is it important to disclose you have DMD

Do you feel it might influence employers' perceptions, have you an example?

What supports would be helpful for young people with DMD in this situation.

Part 3

Generally speaking, how do you think having a disability experience influences a young person's experience of growing up and becoming an adult. What do you feel would be useful for young people to know about when beginning to consider their adult future? Being more specific to DMD what are the challenges for young men living with the condition when thinking about transition to adulthood e.g. the time when you are leaving school and making decisions about your life. Can you tell me about the level of support available for young people at this time? Have you any examples of supports you found helpful? Would you say living with DMD is more challenging than it may be for young people with different diagnosis or condition? How does living with a condition which has ongoing medical needs and disease progression influence a young person during the years of transition to adulthood? Was this a factor in your decision making at the time? What type of support if any helped you during this time
Results of this study are going to be used to develop supports and programmes for young people to assist them in preparing to leave school and move into adulthood. Would you have any suggestions of what this might look like? Have you any examples of supports or interventions or specific programmes that helped you If you could go back in time, what type of supports would you like or can you tell me what would have been helpful for you. Would a peer support network have been helpful for you; can you explain why or why not? Is there anything you feel people in general should know about relating to experiences of people growing up with DMD. What would help teenagers to prepare for new situations they will be in? Can you think of anything that might have helped or enhanced your experience of growing up into adulthood? Is there anything else that we haven't talked about that you would like to add.

Appendix 6: Interview Guide – Parents

Interview

Welcome and thank you for agreeing to participate in this interview. I am interested to hear your personal experiences of your child growing up and preparing for adult life. I'd like to hear what challenges you saw them encounter and any ideas you may have of things that helped you or would help young people and their families prepare for this time.

You can talk about your own experience or in general about what your thoughts are on these experiences for other parents of children with Duchenne Muscular Dystrophy

At any time, you can take a break or chose to stop the interview.

Part One

Can you describe your child's teenage years (current or in the past depending on the age of the child)? What is/was going on in their lives (prompts: school, leisure, health, service provision)?

Do you have any worries about what the transition to adulthood would be like for them? / At that time were you thinking about what the transition to adulthood would be like for them? Did you have any worries about what growing up into an adult would be like for them?

Do you think your child is being prepared or is prepared for growing up? / Looking back what preparation was happening or not for your child to grow up/become an adult?

Do you / Did you think about their adult future and what that it might look like? As they were growing up through the teenage years what expectations did you have, if any, for them for adulthood?

For example, were you involved with different services, were hospital visits a large part of your life, how was your child's health during those years.

What type of supports are/were available for your child during those teenage years?

Is there/Was there support available for you as a parent at this time also, can you tell me more about this support?

(as a teenager) Are any transition specific support services/preparation available to your child? Were any transition specific support services/preparation available to your child?

Part Two

As your child finished with school how did that impact on you?

What was this next step like for your child? Can you tell me a bit about this stage of life, what new challenges did your child / did you face?

Were there supports in place to help with this transition? If so, were they helpful?

If not, what were the challenges?

What type of supports would you like to see being made available at this time?

How does Duchenne Muscular Dystrophy influence the transition period?

How was this time for you and your child? Did you feel supported, by who and how?

What did your child do after finishing with school? Did they have expectations of what they would like to do? Were there supports in place to support them achieving this?

Thinking back a little, can you tell me again what expectations you had or hopes you had for your child as they grew to adulthood?

Part Three

So now your child is living an adult life, is it how you imagined it?

Did the worries and concerns you had when they were younger materialise?

Do you now have new worries and concerns for your child?

Do you see your child as having an independent adult life

If yes – can you tell me what makes you say this

If no – why do they not have an independent life, can you tell me more about this

Have you concerns about medical issues, deteriorating health, shorter life expectancy. Does this impact on having an independent life, does it impact on your expectations for your child

If you have other children how did your expectations differ for your child with DMD to the others? Can you describe this?

Reflecting on your adult child do you feel you still need to advocate and be a voice for your child? Do they choose to advocate for themselves? (prompt to describe further)

Ideas around preparation during adolescence

In general, what supports would you like to see in place to support young people with Duchenne Muscular Dystrophy transitioning to adulthood

What suggestions do you have for supports/programme development to assist young people in preparing for time when they leave school and children's services?

Appendix 7: Interview Guide – Service Providers

Interview

Welcome and introduction.

I am exploring the transition to adulthood or growing up experiences of people with Duchenne Muscular Dystrophy (DMD). We are interviewing adults with muscular dystrophy, the parents of teenagers or adults with DMD and people who are involved in providing services to children and adults with DMD and their families.

From service providers we are particularly interested in hearing about what services and supports are being provided during the years associated with moving into adulthood and thoughts on what supports or services might be helpful to prepare for the transition to adulthood and during the transition to adulthood.

You can talk about your own experience as a service provider or generally what your thoughts are.

Ground rules

Please offer your opinion and answer any of the questions you feel you can contribute too. You can talk about your own experience or in general.

Part One

Can you tell me what your role or your profession is and your involvement now or in the past with children or adults with DMD and their families.

If you are working in children's services:

What if any is your current role with teenagers and their families around preparing for moving into adulthood? Is this being addressed within your discipline/service? If so, what does this look like, who is involved, is there a formal structure?

In your opinion are young people with DMD being prepared for moving into adulthood? (Describe, how, by who etc)

Have you contact with, or do you hear what it's like for your young adult service users after transition from your services? Are you aware of what they did or where they went? E.g., day services, further education, looking for a job, living independently in the community? Is there a pathway in place to support transition to adulthood, can you tell me about this.

Are you involved in discussion around transition planning? Is this related to transition to adult services or more general decision making about becoming an adult?

If so, what are the main challenges identified? What, if any interventions, does your service provide to support young people at this life stage – Key worker? Information?

If not what interventions, supports would you like to see offered? How do you think this would look

What do you see as the needs of people with DMD in relation to transitioning to adulthood? What are the main challenges that they are facing (describe these, what is contributing to this, are these needs being addressed and if so describe, what might address these needs/how might these needs be addressed)

Who are the key people that you think should be involved in preparing young people with DMD for transition to adulthood.

Do you feel issues such as knowing about and understanding their medical condition (specifically Duchenne Muscular Dystrophy) and future medical needs are addressed? How are young adults skilled to manage their own medical care into the future? Who addresses this, who is involved. Does the service user seek this information? If it's not addressed, should it be and why and how? What type of support would you like to see being offered.

Is there an opportunity to address how young people can manage their emotions and talking to their peers and others about DMD throughout the transition journey e.g.

- how to deal with unwanted comments; how to cope with emotions such as anger/anxiety/sadness; feeling comfortable dealing and co-ordinating carers; how to manage relationship with young carers of similar age to them; concern for the future; maintaining friendships & forming adult relationships. What does this look like, can you tell me how it's addressed. How would you like to see this addressed.

<u>Things that helped.</u>

Are you aware of any supports or things in general, not exclusively linked to your service, which made these experiences easier for adolescents/young adults?

What would have been helpful for your young clients with Duchenne Muscular Dystrophy during this time?

Are you aware if your service users are connected too, or are around others with a similar life limiting condition to theirs? If yes is this helpful? How? If no, would it have been? Why?

From your experience are you aware of supports or strategies that were useful for the transition process? What would have been useful?
Ideas around preparation during adolescence Can you think of anything that would help teenagers to prepare for these new situations that they will be in? What in their life/in the interventions they were receiving was helpful in preparing for moving into adulthood? What suggestions do you have for supports/programme development to assist young people in preparing for time when they leave school and children's services? Are there specific supports or life skills that would be helpful to support young people with their journey to adulthood.

Appendix 8: Information Flyers – Young Men; Parents; Service Providers

Calling adults with Duchenne Muscular Dystrophy to share their experiences of moving into adulthood

If you are 18 years or over and have Duchenne Muscular Dystrophy we would like to hear from you and have you share your experiences of the transition to adulthood with us.

We are doing research to assist us in creating resources for teenagers with Duchenne Muscular Dystrophy to help them prepare for moving into adulthood.

What's involved? An individual interview online or in person with Siobhán O' Shea, postgraduate researcher, Discipline of Occupational Therapy, Trinity College Dublin if you choose to take part.

For more information email osheas7@tcd.ie

This research is being carried out by The Discipline of Occupational Therapy, Trinity College Dublin in collaboration with Muscular Dystrophy Ireland

Are you a parent or caregiver to a teenager/young adult with Duchenne Muscular Dystrophy?

If you are a parent or caregiver to a teenager/young adult with Duchenne Muscular Dystrophy we would like to hear from you and have you share your concerns, expectations and hopes with us.

We are doing research to assist us in creating resources for teenagers with Duchenne Muscular Dystrophy to help them prepare for moving into adulthood.

What's involved? An individual interview, online, with Siobhán O' Shea, postgraduate researcher, Discipline of Occupational Therapy, Trinity College Dublin if you choose to take part.

For more information email osheas7@tcd.ie

This research is being carried out by The Discipline of Occupational Therapy, Trinity College Dublin in collaboration with Muscular Dystrophy Ireland

STAR
Supporting Transitions to Adulthood Resources project
DMD Research

Do you work with teenagers/young adults with Duchenne Muscular Dystrophy?

If you work with teenagers/young adults with Duchenne Muscular Dystrophy I would like to hear from you and have you share your perspective on service provision relating to transition to adulthood.

We are doing research to assist us in creating resources for teenagers with Duchenne Muscular Dystrophy to help them prepare for moving into adulthood.

What's involved? An individual interview, online, with Siobhán O' Shea, postgraduate researcher, Discipline of Occupational Therapy, Trinity College Dublin if you choose to take part.

For more information email osheas7@tcd.ie

This research is being carried out by The Discipline of Occupational Therapy, Trinity College Dublin in collaboration with Muscular Dystrophy Ireland

Appendix 9: Study Invitation – Young Men; Parents; Service Providers

Introductory letter for recruitment - young men

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Date

Research study: **Supporting Transitions to Adulthood Resources (STAR) Project**.

Dear ,

I am attaching all of the study information.

We are interested in talking to adults, aged 18 years and older, with physical and sensory impairments about their experiences in the years associated with transitions to adulthood. Previous research has shown that leaving school and moving into other life areas such as further study, work or moving out of home can be challenging. We would like to find out what people's experiences were and what supports might help to prepare young people earlier on in adolescence to be ready for these changes. We will use the information that we gather to design supports for young people. The study is being carried out in Trinity College Dublin by Michelle Spirtos, Discipline of Occupational Therapy, Siobhan O'Shea, Postgraduate student Discipline of Occupational Therapy, Robbie Gilligan, Social Work and Cliona Horan who is an independent researcher with personal experience in this.

I am writing to invite you to take part in a focus group meeting (either online or in person) with other young people or in an individual interview with you by yourself. All of the study information is attached. This includes an information leaflet which will tell you about the study and the consent form that you will sign if you decide to take part in the study.

Your participation in the study is voluntary and you can choose not to become involved. This will not effect any services that you are receiving.

We would be grateful if you would read the attached study information. If you are interested in participating in the study or would like to receive further information about the study we ask you please to either text/telephone Michelle Spirtos on 0877552362 or email osheas7@tcd.ie.

Thank you very much.

Yours sincerely,

Michelle Spirtos, Discipline of Occupational Therapy, Trinity College Dublin

Siobhan O'Shea, Postgraduate Student, Trinity College Dublin

Cliona Horan, Independent Researcher

Robbie Gilligan, Social Work, Trinity College Dublin

Introductory letter for recruitment (parents)

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Date:

Dear

My name is Siobhan O' Shea and I am a qualified Occupational Therapist working parttime in the Central Remedial Clinic and I am currently completing a Master's research study in the Discipline of Occupational Therapy, Trinity College Dublin. This research study is concerned with understanding the experience of transition to adulthood for young people with Duchenne Muscular Dystrophy (DMD).

In the past decades there has been considerable strides in the medical interventions and management available to young people with a diagnosis of DMD with young people experiencing greater life expectancy. But how services support young people with DMD to become adults has not been given enough attention. We are seeking to understand the experiences and needs of young people which will assist us in developing supports and strategies to prepare and support young people to become adults.

I am interested in gathering the views of parents/caregivers on the experiences of young people with DMD. I am interested in examining how preparing for adulthood is currently being supported and to determine what may be of benefit to young people.

If you are a parent of a teenager, aged 15 or over, or a parent of an adult with a diagnosis of DMD I would like to invite you to take part in a short semi-structured interview. Your participation in the study is voluntary and you can choose not to become involved.

This will take place virtually using Zoom. During the interview I am interested to hear your personal experiences of your child growing up and preparing for adult life. I'd like to hear what challenges you saw them encounter and any ideas you may have of things that helped you or would help young people and their families prepare for this time.

I would be grateful if you would read the attached study information. If you are interested in participating in the study or would like to receive further information about the study, please email me, Siobhan O' Shea - osheas7@tcd.ie

Please feel free to forward this email invitation and attached Participant Information Leaflet to other parents you feel may be interested in participating in this study.

Thank you for your time.

Yours sincerely,

Siobhan O' Shea

osheas7@tcd.ie

Introductory letter for recruitment (Service Providers)

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Date

Dear

My name is Siobhan O' Shea and I am a qualified Occupational Therapist working parttime in the Central Remedial Clinic. I am currently completing a Master's research study in the Discipline of Occupational Therapy, Trinity College Dublin. This research study is concerned with understanding the experience of transition to adulthood for young people with Duchenne Muscular Dystrophy (DMD).

I am interested in hearing from anyone who has experience of providing services to teenagers and/or adults with Duchenne Muscular Dystrophy (DMD). I am interested in gathering service providers perspective on service provision relating to transition to adulthood, what supports are currently in place or which supports would be beneficial to assist young people in preparing for, and during, transitions to adulthood.

If you are currently working or have experience of working with people aged 15 years or over (including adults) with a diagnosis of DMD I would like to invite you to take part in a short semi-structured interview. Your participation in the study is voluntary and you can choose not to become involved.

This will take place virtually using Zoom. During the interview I am interested to hear your views on how preparing for adulthood is currently being supported and to determine what may be of benefit to young people. I'd like to hear what challenges may be encountered and any ideas you might have of things that helped you or would help young people and their families prepare for this time.

I would be grateful if you would read the attached study information. If you are interested in participating in the study or would like to receive further information about the study, please email me, Siobhan O' Shea, osheas7@tcd.ie

Please feel free to forward this email invitation and attached Participant Information Leaflet to other service providers you feel may be interested in participating in this study.

Thank you for your time.

Yours sincerely,

Siobhan O’ Shea

osheas7@tcd.ie

Appendix 10: Participant Information Leaflet – Young Men; Parents; Service Providers

Participant Information Leaflet – young men

Supporting Transitions to Adulthood Resources Project

Site:	Trinity College Dublin
Principal Investigator	Michelle Spirtos
Co-Investigators:	Siobhan O'Shea (postgrad student)
	Robbie Gilligan
	Cliona Horan
Data Controllers:	Trinity College Dublin
Data Protection Officer:	Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2

You have been invited to take part in a research study which is being completed by Trinity College Dublin. Michelle Spirtos is the principal investigator. Before you decide if you wish you to take part, please read this information sheet carefully. Ask Michelle or Siobhan any questions. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family, friends or GP.

Part 1: The Study

What is being done?

This study is being done to look at the challenges faced by young people with physical or sensory impairments during transitions to adulthood like leaving secondary school, getting

a job, going to post-secondary education or meeting other young people socially. It is also looking at what supports might help to prepare young people for these things.

Why have I been invited to take part?

We are doing this study to understand better what the challenges are for young people in moving into adulthood and what supports could be helpful and we will use this information to develop supports for young people.

You have been invited to participate in this study because you are aged 18 years or older and have a physical or a sensory impairment.

We aim to involve young people in focus groups (group discussions) about their experiences in small groups of 6 to 12 or in individual interviews with the researcher.

Do I have to take part? Can I withdraw?

You do not have to become involved. If you chose not to be involved in the study this will have no adverse consequences and will not affect your receipt of any services that you are receiving now or in the future. You can decide to withdraw from the study at any time up until 2 weeks after the focus group/interview has taken place. At that point we will have removed any potentially identifying information from the transcripts and your comments and contribution to the discussion will have been added with others and pseudonymised.

If you wish to withdraw contact Michelle Spirtos on 01-8963213 or 0877552362

How will the study be carried out?

It is expected that we will run different focus groups throughout Ireland. Each group will have 6-12 young people and will be somewhere convenient to you (including an online option). We hope to run 3 to 5 focus groups at different places in Ireland. During the focus groups we will assist participants to discuss challenges around moving into adulthood and what supports might be helpful in preparing young people for this. If you prefer to do this individually, we will do an interview with you either in person or online.

What will happen to me if I decide to take part?

If you decide to take part in the study, you will be invited to attend a focus group at a location convenient to you (this may be in person or online). Six to 12 people around your age will be taking part and the group will last 60-90 minutes. In the group we will discuss challenges that people with physical and sensory impairments can face during moving into

adulthood and the supports that might help young people to prepare. You will be asked to share your ideas and experiences but only if you want to as the questions will be to the whole group. If you do join in the discussion, it will be up to you what you want to share with the others in the group. If you take part in an interview this will last up to one hour. If you choose instead to do an interview with the researcher this will ask the same questions and can be in person or virtual.

What will happen to my data?

We will be audio recording the focus groups and interviews. We will transcribe what everyone has said into a written document and once we have checked that the written document is accurate, we will destroy the audio recording. In the written document we will remove any information that will identify people such as names if people use them or names of services. The information from your focus group (or interview) will be put with the information from the other focus groups we run and will become pseudonymised. We will then analyse and look at this information and use it to help us to develop supports and programmes to help to prepare young people for moving into adulthood. We will also publish the findings in academic journals and conferences. You can request a copy of your focus group or interview transcript.

Are there any benefits to taking part in this research?

At the moment there is very little written about the challenges young people with physical and sensory impairments can face as they meet new people and are involved in transitions such as getting a job or going out socialising. By taking part in this study, it will provide information on what supports or programmes might be useful, and this should be of benefit to other young people to help to prepare them for moving into adulthood. Your opinion can help us to make changes for other young people. If you take part in one of the focus groups, you will get a chance to talk to other young people who may have had a similar experience to you.

Are there any risks to me or others if I take part?

There are no risks to taking part in in this study. If you had some difficulties with areas we will be discussing this might be upsetting for you. If this happens you can take a break and leave the group or interview for a while or decide to stop taking part. You will only have to

talk if you want to as we will ask questions to everyone, and people can chose to be part of the discussions. What people have said in all the focus groups (or interviews) will be put together and analysed and looked at by the researchers and no participants will be individually identified.

If you are finding your experiences upsetting there are organisations such as the Samaritans (Phone 116 123) or Turn2Me (www.turn2me.ie) where you can avail of support.

Will I be told the outcome of the study?

If you would like to have a summary of the findings of the study, you can let us know and we will share this with you. We will not be able to tell you about your own parts of the discussion as we will have put all the findings from the focus groups (or interviews) together.

Part 2: Data Protection

What information about me will be used as part of this study?

In order to contact you to schedule you will need to provide your first name and your telephone number or email to the researchers. This is the only identifiable information that we will gather. Anything that you say in the focus group or interview will be recorded but if it contains any identifying information, we will remove this from the transcript.

The consent form that you will sign to take part will be kept in a locked cabinet for a period of 7 years and then destroyed.

Will my personal data be kept confidential? How will my data be kept safe?

The consent form will be kept in a locked cabinet for seven years and then destroyed.

A Data Protection Impact Assessment was carried out and the risk was considered very low.

All of the persons involved in carrying out this research project are bound by professional codes of secrecy or contractual codes of secrecy that will protect your confidentiality.

Training in data protection law and practice has been completed by the individuals involved in carrying out the research.

What is the lawful basis to use my personal data?

By law, we can use your personal information for scientific research (in the public interest). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights in relation to my personal data?

You are entitled to receive a copy of your data (from your focus group or interview) in a portable format and to have it transferred to another data controller.

You can exercise these rights by contacting your study principal investigator, Michelle Spirtos, spirtosa@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Part 3: Future Research

Will my personal data be used in future studies?

The findings for this research will only be used for this project which aims to develop resources and programmes for young people.

Part 4: Further Information

Has this study been approved by a research ethics committee?

This project has ethical approval from the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin granted on December 2nd 2022.

Who is organising and funding this study? Will the results be used for commercial purposes?

There is no funding for this project external to Trinity. Research seed funding received from the School of Medicine, Trinity College Dublin will be used to support completion of the project. Findings will not be used for any commercial purposes.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we will not be paying people to take part. There will be no cost to you to take part apart from any costs related to travelling to the focus group or interview that you might have.

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact Michelle Spirtos at 0877552362 or spirtosa@tcd.ie or the Trinity Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

We do not intend to contact you following your participation in the study.

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.

Participant Information Leaflet - parent

Name of Study: Understanding the Experience of Transition to Adulthood for Young People with Muscular Dystrophy

Site	**Trinity College Dublin**
Principal Investigator(s) and Co-Investigator(s)	Siobhan O' Shea Investigator osheas7@tcd.ie Senior Occupational Therapist, CRC & TCD Research student Michelle Spirtos Supervisor spirtosa@tcd.ie Assistant Professor, Discipline of Occupational Therapy, TCD
Data Controllers	Trinity College Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2

You are being invited to take part in a research study that is being completed by Siobhan O' Shea at the Discipline of Occupational Therapy, Trinity College Dublin as part of post graduate study.

Before you decide on participating, please read this information sheet carefully. You can ask us if there is anything that is not clear or if you would like more information. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may want to discuss this with other people before deciding to take part. Thank you for reading this.

Do I have to take part?

No, you don't have to take part in this study. It is entirely voluntary and up to you. If you decide not to take part, it will not have any negative impact on you or the person you care for either now or in the future. Don't feel rushed or under pressure to take part or to make

a quick decision. You can change your mind and opt out at any time even if the study has started.

This leaflet has five main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Further Information

Part 5 – Next steps

Part 1 – The Study

Why have I been invited to take part?

You have been invited to participate in this study because you are the parent/caregiver to a teenager or adult with Duchenne Muscular Dystrophy and you have received an information pack regarding the research and have contacted the researcher for additional information. We are hoping to have 10 parent/caregivers of young people with DMD and 10 service providers take part in this research.

Why is this study being done?

This study is being done to explore the challenges faced by young people with Duchenne Muscular Dystrophy (DMD) during transitions to adulthood.

Previous research has shown that leaving school and moving into other life areas such as further study, work or moving out of home can be challenging. I am interested to examine how preparing for adulthood is currently being supported and to determine what may be of benefit to young people.

How we support young people with DMD to become adults has not been given sufficient attention, and it is necessary to first understand their needs and use this information to develop supports and strategies to help prepare young people for this transition to adulthood.

What does taking part in the study involve?

If you decide to take part, a member of the research team will discuss this information leaflet and consent form with you. It should take about half an hour to take you through the consent process and answer any questions you may have. You will be given a copy of your signed consent form and this leaflet to keep.

Taking part in the study will involve taking part in an interview with Siobhan, which will take approximately one hour.

We will arrange a time and location for your one-to-one interview. With your permission, the interview will be audio recorded.

During the interview you will be asked questions about your concerns or expectations regarding the challenges experienced by young people with DMD moving into adulthood and what hopes or supports you think might be helpful in preparing young people for this. The interview will take place online via ZOOM.

Siobhan will transcribe the interview using word, checking the transcript for accuracy. You do not have to answer any question you do not want to.

What information about me (personal data) will be used as part of this study?

If you would like to have a copy of the written transcript from your interview you can let me know and it can be shared with you. Please request your transcript within two weeks following your interview, the information from your interview will be put with the information from other participant interviews and will become pseudonymised.

What are the possible benefits of taking part?

Taking part in this study may not directly benefit you. However, we hope that this research may help us to develop supports and strategies to help prepare young people for transition to adulthood.

Are there any possible disadvantages or risks from taking part?

There are no known risks involved in this study. At all times, the well-being of participants takes priority over research activities.

In the event of the interview triggering an emotional event, the interviewer will stop the session and advise you to contact there are organisations such as the Samaritans (Phone 116 123) or Turn2Me, http://www.turn2me.ie, where you can avail of support.

Data Breach: we take many measures to ensure the confidentiality of all data and the risk to you of a breach of confidentiality is considered very low.

What will happen to the results of the study?

The results of the study may be reported in medical/scientific/educational journals and disclosed at medical/scientific conferences. No information which reveals your identity will be disclosed.

No information which reveals your identity will be disclosed.

Part 2 – Data Protection

We will use the following information about you, we will collect your contact details to arrange the interview, the audio recording of your interview and the final transcript.

Who will access my personal data?

Only the principal researcher will be able to identify you. The PI will replace your name with a code on all research data.

The study supervisor may require access to the research data to ensure academic rigour.

How is the information kept confidential and secure?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality. We replace your name with a code to ensure your confidentiality. Only the PI can link the research data back to you. All research data is held securely on TCD Microsoft Office 365 provided platforms, with access restricted to the research team listed above.

A data protection impact assessment was carried out and the risk identified was low.

Limitation to Confidentiality.

Confidentiality may be breached in circumstances in which the research team has a strong belief or evidence exists that there is a serious risk of harm or danger to you or another individual. Disclosure may also be required as part of a professional code, legal process, or Garda investigation. In such instances, information may be disclosed to significant others or appropriate third parties without permission from you being sought. Where possible, a full explanation will be given to you regarding the necessary procedures and the intended actions that may need to be taken.

How long will my personal data be needed?

Your consent form will be retained for a period of seven years, as per department policy, and then securely deleted as the legal basis for processing the data.

The audio recording of the interview will be retained until it has been transcribed and the content verified after which it will be securely deleted.

The coded interview transcripts with all identifying information removed will be retained for a period of two weeks after which time the link between you and your personal data will be securely deleted.

What is the lawful (legal) basis to use my personal data?

By law,[1] we can use your personal information for scientific research[2] (in the public interest[3]) which we hope will improve the [insert the public interest case here]. We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations but we do not rely on this as our legal basis under GDPR.

What are my rights in relation to my personal data?

[1] The European General Data Protection Regulation (GDPR)

[2] *Article 9(2) (j))*

[3] *(Article 6(1)(e)*

You are entitled to:

- object to our use of your personal data or any further use;
- request access to your personal data and to receive a copy of it, up to two weeks after the interview;
- request inaccurate personal data be corrected or deleted;
- request restriction of our use of your personal data;
- request deletion of your personal data.

By law you can exercise the above rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. For example, if the study is about to be published then we may not be able to delete data as it would impact on the results.

You can exercise these rights by contacting your study principal investigator, Siobhan O' Shea, the research supervisor Michelle Spirtos, spirtosa@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Part 3 - Approval, Organising and Funding

Has this study been approved by a research ethics committee?

Yes, this study has ethical approval from The School of Medicine, Level 2, Research Ethics Committee, Trinity College Dublin granted on 31/01/2002 Reference No: 2916

An annual report will be provided to the REC and on completion of the study.

Who is organising and funding this study?

This study is being undertaken by Siobhan O'Shea as part of their academic studies. She has received a bursary to cover course fees.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying you to take part in the study. There will be no cost to you to take part.

Part 4 – Further Information

What happens if I change my mind?

Your participation in this study is voluntary and you can change your mind up to two weeks after the interview. After this time, any identifying information will have been

removed from the transcript, the audio recording will have been deleted and all the interview transcripts will be grouped for analysis.

You do not have to give a reason for changing your mind. This will not have any negative impact on you.

If you would like to withdraw from the study, please contact Siobhan O' Shea osheas7@tcd.ie who can organise this for you.

We will discuss with you if you are happy for us to continue to use information about you (personal data) which has already been collected. If you do not consent to your personal data being retained for this study, we will delete any information that could identify you.

Please note that we will not be able to remove personal data which has been shared or pooled for use in publication before your request for deletion.

We will not contact you again.

Who should I contact for information or concerns?

If you have any concerns or questions you can contact:

Study Supervisor Michelle Spirtos at 0877552362 or spirtosa@tcd.ie

If you have any questions in relation to your rights under Data protection law, you can contact Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

I do not intend to contact you following your participation in the study.

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.

Participant Information Leaflet - service provider

Name of Study: Understanding the Experience of Transition to Adulthood for Young People with Muscular Dystrophy

Site	**Trinity College Dublin**
Principal Investigator(s) and Co-Investigator(s)	Siobhan O' Shea Investigator osheas7@tcd.ie Senior Occupational Therapist, CRC & TCD Research student Michelle Spirtos Supervisor spirtosa@tcd.ie Assistant Professor, Discipline of Occupational Therapy, TCD
Data Controllers	Trinity College Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2

You are being invited to take part in a research study that is being completed by Siobhan O' Shea at the Discipline of Occupational Therapy, Trinity College Dublin as part of post graduate study.

Before you decide on participating, please read this information sheet carefully. You can ask us if there is anything that is not clear or if you would like more information. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may want to discuss this with other people before deciding to take part. Thank you for reading this.

Do I have to take part?

No you don't have to take part in this study. It is entirely voluntary and up to you. If you decide not to take part, it will not have any negative impact on you or the person you care for either now or in the future. Don't feel rushed or under pressure to take part or to make a quick decision. You can change your mind and opt out at any time even if the study has started.

This leaflet has five main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Further Information

Part 5 – Next steps

Part 1 – The Study

Why have I been invited to take part?

You have been invited to participate in this study because you are a service provider working with a teenager or adult with Duchenne Muscular Dystrophy and you have received an information pack regarding the research and have contacted the researcher for additional information. We are hoping to have 10 parent/caregivers of young people with DMD and 10 service providers take part in this research.

Why is this study being done?

This study is being done to explore the challenges faced by young people with Duchenne Muscular Dystrophy (DMD) during transitions to adulthood.

Previous research has shown that leaving school and moving into other life areas such as further study, work or moving out of home can be challenging. I am interested to

explore how preparing for adulthood is currently being supported and to determine what may be of benefit to young people.

How we support young people with DMD to become adults has not been given sufficient attention, and it is necessary to first understand their needs and use this information to develop supports and strategies to help prepare young people for this transition to adulthood.

What does taking part in the study involve?

If you decide to take part, a member of the research team will discuss this information leaflet and consent form with you. It should take about half an hour to take you through the consent process and answer any questions you may have. You will be given a copy of your signed consent form and this leaflet to keep.

Taking part in the study will involve taking part in an interview with Siobhan, which will take approximately one hour.

We will arrange a time and location for your one-to-one interview. With your permission, the interview will be audio recorded.

During the interview you will be asked questions about your perspective on service provision relating to transition to adulthood and challenges experienced by young people with DMD moving into adulthood. We would like to hear what supports you think might be helpful in preparing young people for this. The interview will take place online via ZOOM.

The interview will be transcribed by Siobhan, checking the transcript for accuracy. You do not have to answer any question you do not want to.

If you would like to have a copy of the written transcript from your interview you can let me know and it can be shared with you. Please request your transcript within two weeks following your interview, the information from your interview will be put with the information from other participant interviews and will become pseudonymised.

What are the possible benefits of taking part?

Taking part in this study may not directly benefit you. However, we hope that this research may help us to develop supports and strategies to help prepare young people for transition to adulthood.

Are there any possible disadvantages or risks from taking part?

There are no known risks involved in this study. At all times, the well-being of participants takes priority over research activities.

In the event of the interview triggering an emotional event, the interviewer will stop the session and advise you to contact there are organisations such as the Samaritans (Phone 116 123) or Turn2Me (www.turn2me.ie) where you can avail of support.

Data Breach: we take many measures to ensure the confidentiality of all data and the risk to you of a breach of confidentiality is considered very low.

What will happen to the results of the study?

The results of the study may be reported in medical/scientific/educational journals and disclosed at medical/scientific conferences. No information which reveals your identity will be disclosed.

No information which reveals your identity will be disclosed.

Part 2 – Data Protection

We will use the following information about you, we will collect your contact details to arrange the interview, the audio recording of your interview and the final transcript.

Who will access my personal data?

Only the principal researcher will be able to identify you. The PI will replace your name with a code on all research data.

The study supervisor may require access to the research data to ensure academic rigour.

How is the information kept confidential and secure?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality. We replace your name with a code to ensure your confidentiality. Only the PI can link the research data back to you.

All research data is held securely on TCD Microsoft Office 365 provided platforms, with access restricted to the research team listed above.

A data protection impact assessment was carried out and the risk identified was low.

Limitation to Confidentiality.

Confidentiality may be breached in circumstances in which the research team has a strong belief or evidence exists that there is a serious risk of harm or danger to you or another individual. Disclosure may also be required as part of a professional code, legal process, or Garda investigation. In such instances, information may be disclosed to

significant others or appropriate third parties without permission from you being sought. Where possible, a full explanation will be given to you regarding the necessary procedures and the intended actions that may need to be taken.

How long will my personal data be needed?

Your consent form will be retained for a period of seven years, as per department policy, and then securely deleted as the legal basis for processing the data.

The audio recording of the interview will be retained until it has been transcribed and the content verified after which it will be securely deleted.

The coded interview transcripts with all identifying information removed will be retained for a period of two weeks after which time the link between you and your personal data will be securely deleted.

What is the lawful (legal) basis to use my personal data?

By law,[4] we can use your personal information for scientific research[5] (in the public interest[6]) which we hope will improve the [insert the public interest case here]. We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations but we do not rely on this as our legal basis under GDPR.

What are my rights in relation to my personal data?

You are entitled to:

- object to our use of your personal data or any further use;
- request access to your personal data and to receive a copy of it, up to two weeks after the interview;
- request inaccurate personal data be corrected or deleted;
- request restriction of our use of your personal data;
- request deletion of your personal data.

By law you can exercise the above rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. For example, if the study is about to be published then we may not be able to delete data as it would impact on the results.

[4] The European General Data Protection Regulation (GDPR)

[5] *Article 9(2) (j))*

[6] *(Article 6(1)(e)*

You can exercise these rights by contacting your study principal investigator, Siobhan O' Shea, the research supervisor Michelle Spirtos, spirtosa@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Part 3 - Approval, Organising and Funding

Has this study been approved by a research ethics committee?

Yes, this study has ethical approval from The School of Medicine, Level 2, Research Ethics Committee, Trinity College Dublin granted on 31/01/2024
An annual report will be provided to the REC and on completion of the study.

Who is organising and funding this study?

This study is being undertaken by Siobhan O'Shea as part of their academic studies. She has received a bursary for her fees.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying you to take part in the study. There will be no cost to you to take part.

Part 4 – Further Information

What happens if I change my mind?

Your participation in this study is voluntary and you can change your mind up to two weeks after the interview. After this time, any identifying information will have been removed from the transcript, the audio recording will have been deleted and all the interview transcripts will be grouped for analysis.

You do not have to give a reason for changing your mind. This will not have any negative impact on you.

If you would like to withdraw from the study, please contact Siobhan O' Shea osheas7@tcd.ie who can organise this for you.

We will discuss with you if you are happy for us to continue to use information about you (personal data) which has already been collected. If you do not consent to your personal data being retained for this study, we will delete any information that could identify you.

Please note that we will not be able to remove personal data which has been shared or pooled for use in publication before your request for deletion.

We will not contact you again.

Who should I contact for information or concerns?

If you have any concerns or questions you can contact:

Study Supervisor Michelle Spirtos at 0877552362 or spirtosa@tcd.ie

If you have any questions in relation to your rights under Data protection law, you can contact Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

I do not intend to contact you following your participation in the study.

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.

Appendix 11: Consent Forms – Young Men; Parents; Service Providers

Participant Informed Consent Form – young men

Supporting Transitions to Adulthood Resources Project

Identification Number for study:

There are 2 sections in this form. Each section has statements and asks you to tick if you agree. **Please ask <u>any</u> questions you may have when reading each of the statements.** **Thank you for participating.** **The end of this form is for the researchers to complete.**	
1. General	**Tick box**
I confirm I have read and understood the **Information Leaflet** for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study **is entirely voluntary. If I decide that I do not want to take part or decide that I want myself and my child to stop taking part in this study that I can do so at any time without giving a reason**. I understand that deciding not to take part will not affect my present or future services.	
I understand that all information will be kept private and confidential and that my name will not be disclosed.	
I understand that I **will not be paid for taking part in this study**[7].	

I know how to contact the research team if I need to.	
I agree to take part in this research study having been fully informed of the **risks, benefits and alternatives** which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researchers by phone/online as part of this research study.	
2. Data processing	**Tick box**
I understand that only the principal investigator will have access to any personal data collected for this study, and that this will not be shared with any third parties as described in the Information leaflet.	
I understand that the benefit to me will be to assist in preparing other young people. I understand that I can request the **transcript from my focus group or interview**.	
I understand that **I can stop taking part in this study** at any time without giving a reason and this will not affect my future services.	
I understand that once my pseudonymised data has been pooled with the data of the other participants that it will not be possible to withdraw my data.	
I consent to the use of my personal data for this study, as described in the information leaflet.	

Participant Name (Block Capitals) Participant Signature Date

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Witness Name (Block Capitals) Witness Signature Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above person the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team

_____

_____

Date

2 copies to be made: 1 for participant, 1 for PI.

Participant Informed Consent Form - Parent

STUDY NAME: Understanding the Experience of Transition to Adulthood for young people with Duchenne Muscular Dystrophy **Identification Number for study:**

There are 2 sections in this form **Section 1** contains statements of understanding and asks you to tick each if you understand. Please ask any questions you may have when reading each of the statements. **Section 2** asks for your informed consent. Please select either 'yes' or 'no' to indicate your choice. **Thank you for participating.** **The end of this form is for the researchers to complete.**

1. General Understanding	**Tick**
I confirm I have read and understood the **Information Leaflet** for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study **is entirely voluntary.** I understand that taking part in this study is entirely voluntary. I understand that not taking part will have no negative impact on me.	
I understand that I can leave this study at any time without giving a reason. I understand that leaving this study will have no negative impact on me, now or in the future.	

I understand that I **will not be paid for taking part in this study**[8]	
I know how to contact the research team if I need to.	
By ticking each box above and choosing my options below <u>and</u> signing this document I agree to participate in this study as described in the Participant Information Leaflet.	
2. Consent	
I agree to take part in this research study having been fully informed of the **risks and benefits** which are set out in full in the information leaflet which I have been provided with.	**Yes** ☐ **No** ☐
I agree to the use of information about me (personal data) including information from the audio recording and transcript of my interview, being used by the research team for this research study as described in the participant information leaflet.	**Yes** ☐ **No** ☐

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Participant Name (Block Capitals) Participant Signature Date

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Witness Name (Block Capitals) Witness Signature Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above person the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team.

_____

Siobhan O' Shea / Michelle Spirtos

Date

2 copies to be made: 1 for participant, 1 for PI.

Participant Informed Consent Form - Service Providers

STUDY NAME: Understanding the Experience of Transition to Adulthood for young people with Duchenne Muscular Dystrophy **Identification Number for study:**

There are 2 sections in this form **Section 1** contains statements of understanding and asks you to tick each if you understand. Please ask any questions you may have when reading each of the statements. **Section 2** asks for your informed consent. Please select either 'yes' or 'no' to indicate your choice. **Thank you for participating.** **The end of this form is for the researchers to complete.**

1. General Understanding	**Tick**
I confirm I have read and understood the **Information Leaflet** for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study **is entirely voluntary.** I understand that taking part in this study is entirely voluntary. I understand that not taking part will have no negative impact on me.	
I understand that I can leave this study at any time without giving a reason. I understand that leaving this study will have no negative impact on me, now or in the future.	

I understand that I **will not be paid for taking part in this study**[9]	
I know how to contact the research team if I need to.	
By ticking each box above and choosing my options below <u>and</u> signing this document I agree to participate in this study as described in the Participant Information Leaflet.	
2. Consent	
I agree to take part in this research study having been fully informed of the **risks and benefits** which are set out in full in the information leaflet which I have been provided with.	**Yes** ☐ **No** ☐
I agree to the use of information about me (personal data) including information from the audio recording and transcript of my interview, being used by the research team for this research study as described in the participant information leaflet.	**Yes** ☐ **No** ☐

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Participant Name (Block Capitals) Participant Signature Date

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Witness Name (Block Capitals) Witness Signature Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above person the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team.

_____

Siobhan O' Shea / Michelle Spirtos

Date

|

2 copies to be made: 1 for participant, 1 for PI.