EXPLORING THE CHALLENGES EXPERIENCED BY PEOPLE WITH MUSCULAR DYSTROPHY LIVING INDEPENDENTLY

(MD INDO-LIVING)

School of Nursing and Midwifery
Trinity College Dublin

Dr Honor Nicholl
Ms Carmel Doyle
Ms Jessica Eustace-Cook
Ms Geraldine Prizeman
Dr Catherine Tracey
Dr Aileen Lynch

Ms Clair Kelly, Muscular Dystrophy Ireland

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Special appreciation is given to Muscular Dystrophy Ireland and in particular to the late CEO, Mr Joe T. Mooney (RIP) and Ms Clair Kelly (Information and Research Officer).

We gratefully acknowledge the MDI members who participated in this study and whose insights and experiences form the basis of this study.
DEDICATION

We dedicate this report to the memory of the late Mr Joe T. Mooney (CEO Muscular Dystrophy Ireland) who was committed and enthusiastic about this study and who shared with us his expertise and support. The research team appreciate his kindness and for facilitating us in all ways possible.

Ar dheis Dé go raibh a anam.
EXECUTIVE SUMMARY

Introduction
This study follows up on the national survey undertaken in 2014 by Muscular Dystrophy Ireland (MDI) in which a questionnaire was distributed to all MDI members (n=697). Significantly, 69% of respondents reported that their condition had a big/very big impact on their independence. With this in mind, the aim of this study was to investigate issues that may impede individuals with muscular dystrophy (MD) from independent living.

The key objectives of the study were to explore the issues which impede individuals with MD from independent living in terms of:
- assistance and support
- supporting and managing health
- the physical environment
- education, employment and further training
- financial implications.

Methodology
A descriptive qualitative study was employed. The sample for this study consisted of adults with MD encompassing all genetically determined muscle wasting conditions. A purposive non-probability sample of thirty one participants was recruited via MDI who acted as the gatekeeper for this study. Ethical approval was obtained from the School of Nursing and Midwifery Research Ethics Committee, Trinity College Dublin. Data collection consisted of four focus group interviews which took place across the country in three different locations. Biographical data were analysed using simple descriptive statistics in Microsoft Excel. All qualitative data were analysed using a combination of data analytical approaches in simple thematic analysis (Halcomb and Davidson 2006; Massey 2011). To protect participants’ identities all participant focus group interviews were coded.
Findings
The findings of this study were categorised under five key headings; assistance and support, supporting and managing health, assistive equipment, physical environment, education, employment and further training, financial implications and voicing for change.

Assistance and support
What was clear from participants in this study was that irrespective of who was involved, some form of assistance and support is essential to facilitate independent living. There was some confusion regarding the precise role of personnel who assist and support people with MD. Above all, many participants were unclear about the role of the PA, what the eligibility criteria are: to acquire PA, to obtain more PA hours when needed in the future, to secure funding and to engage with the application process.

Supporting and managing health
Health professionals’ knowledge levels regarding MD were considered by participants to be highly variable. The wait lists to access health professionals and diagnostic tests are prohibitively long such that people with MD end up self-funding appointments so as to avoid pain and discomfort and to continue to live independently. Multidisciplinary teams and GPs were praised for the important roles they play in supporting the health of people with MD.

Participants were not aware of the range of entitlements that were available to people with MD. In an effort to reduce the health-related costs for people with MD, participants suggested that diagnostic tests be free and that the medical card would be made available to all.

Assistive equipment
There are considerable delays with acquiring and repairing assistive equipment. In particular, many participants had experienced delays with repairing their wheelchairs and highlighted that being without a wheelchair had negatively impacted on their autonomy and independence. Participants had a preference for owning essential medical equipment and in the context of home security, would welcome free monitoring.

Physical environment
The application process for housing adaptations and payment arrangements vary geographically. In some cases adaptions to participants’ houses were not fit for purpose and did not take into account the individual needs of the person with MD. Outside of the home environment, many public buildings, facilities and amenities are unsuitable and
inaccessible to people with a physical disability and do not comply with recommended standards, despite legislation. Many public buildings do not meet disability-friendly or wheelchair-friendly standards despite claiming otherwise.

**Education, employment and further training**

Having adequate supports available while in the education system impacts on opportunities for further education and employment later. Participants were confused about which benefits and entitlements would have to be relinquished should they return to the workforce. Participants queried if the Public Sector was fulfilling the recommended 3% quota of employees with a disability. There were many challenges reported in the context of engaging with employment and these include: not having transport, not having a PA or insufficient PA hours, inaccessible buildings and the unavailability of assistive technologies in the workplace.

**Financial implications**

MD impacts financially on people with the condition and the cost associated with the condition includes: paying for assistance and support, medical- and health-related costs, assistive equipment, housing adaptations and reduced opportunities to engage fully with education, further training and employment.

**Voicing for change**

Participants agreed that there needs to be a clear pathway from diagnosis onwards and that the services that are currently available to people with MD are better resourced. There was also consensus that there should be one go-to organisation which would provide consistent information, source funding and PAs and process relevant applications on behalf of people with MD. Having one organisation would remove the inequity that exists when services and entitlements are compared nationally.
Recommendations

Assistance and support

In the context of assisting and supporting people with MD, there is a need to:

- Define and clarify the roles and duties of the personnel who assist and support people with MD
- Clarify the eligibility criteria and application process when applying for a PA
- Have one organisation to manage all aspects of the PA service.

Supporting and managing health

- Health professionals need to inform themselves about MD so that they can provide MD-related information at the time of diagnosis
- Health professionals need to be educated about the role of the PA (who may need to be present when the person with MD engages with health professionals), their services in both the community and hospital settings
- The time to access health professionals, diagnostic tests and health-related entitlements needs to be reduced
- The range of health-related entitlements available to people with MD needs to be better publicised
- The Long-Term Illness Scheme should cover the cost of medical equipment and all MD-related medications
- The medical card should be available to all people with MD irrespective of means.

Assistive equipment

Participants recommended that:

- The acquisition and repair of assistive equipment be expedited
- They could have the option of purchasing essential medical equipment (rather than renting it on a long-term basis) but that service agreements be included
- People with MD should have access to free home security monitoring.

Physical environment

Participants recommended that:

- The application process and acquisition of funds for adapting houses needs to be streamlined nationally
- Stage-wise payments are available to assist with financial budgeting
- Grants be flexible to meet the needs of people with MD if/as their condition changes
- Adaptations to a person’s house are tailored to the person with MD’s needs
• Public buildings and areas comply with disability-friendly and wheelchair-friendly standards in line with legislation.

**Education, employment and further training**

Participants recommended that:

• Supports are available from childhood onwards when engaging with the education system
• There is clarity around which benefits and entitlements are surrendered when one steps back into education or the work force
• The Public Sector organisations are encouraged to meet the target of employing 3% of their workforce with a disability
• Employers consider the challenges faced by people with disabilities engaging with employment and that they take steps to reduce these, for example, making the building more accessible and providing suitable assistive technologies.

**Financial implications**

Participants recommended that:

• Energy companies consider reviewing their tariffs for people with a physical disability
• Government assesses the true cost and financial impact of having a disability and make realistic provisions thereafter.

**Voicing for change**

Participants recommended that:

• There is a clear pathway for people with MD from diagnosis onwards
• Current services are better resourced
• There is a one organisation (one stop shop) which would provide consistent information, source funding and PAs and process relevant applications on behalf of people with MD.
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# Glossary of Terms

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<td>CIL</td>
<td>Centre for Independent Living</td>
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<td>CSO</td>
<td>Central Statistics Office</td>
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<td>DMD</td>
<td>Duchenne muscular dystrophy</td>
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<td>ENIL</td>
<td>European Network on Independent Living</td>
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<tr>
<td>ESRI</td>
<td>The Economic and Social Research Institute</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>HSE</td>
<td>Health Service Executive</td>
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<tr>
<td>IL</td>
<td>independent living</td>
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<tr>
<td>MD</td>
<td>muscular dystrophy</td>
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<td>MDI</td>
<td>Muscular Dystrophy Ireland</td>
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<td>MG</td>
<td>myasthenia gravis</td>
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<td>NAG</td>
<td>National Advisory Group</td>
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<td>NDA</td>
<td>National Disability Authority</td>
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<tr>
<td>OT</td>
<td>occupational therapist</td>
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<tr>
<td>PA</td>
<td>Personal Assistant</td>
</tr>
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<td>UK</td>
<td>United Kingdom</td>
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CHAPTER 1 BACKGROUND

1.1 Muscular dystrophy and Muscular Dystrophy Ireland

Muscular Dystrophy (MD) is the collective name for a group of genetic neuromuscular conditions characterised by the progressive weakening and wasting of the muscles (Dreyer et al. 2010a; Baker 2014; Muscular Dystrophy Ireland (MDI) 2014a). There are several types of MD that can affect both adults and children. Some forms are present at birth or in childhood, and others manifest later in life (Baker 2014; MDI 2014a). In Ireland, the most common form of MD, Duchenne Muscular Dystrophy occurs in about 1 in 3,500 males (National Centre for Medical Genetics 2015).

There is no single source indicating the number of people affected by the condition in Ireland. However, as of 18th March 2015, MDI, a voluntary organisation established to support families who have a member with muscular dystrophy, had 697 registered members with neuromuscular conditions. This figure represents an increase of 192 since May 2009 (MDI 2014a). MDI also supports the extended families of people with neuromuscular conditions, including parents, carers and siblings, and provides support and information to healthcare and educational professionals. One of MDI’s objectives is to “promote, through practical empowerment, independent living for people with the condition” (MDI 2014b:1).

In 2014, MDI carried out a National Survey on its members (n=670) to determine their opinions on a range of issues such as medical services, housing, equipment, personal assistance, education, training and employment (MDI 2014a). A substantial number of respondents (69%) reported that their condition had a big/very big impact on their independence. Therefore the aim of the study presented in this report was to further investigate the factors which impede people with MD from living independently. With that in mind, the concept of independent living will be explored next.

1.2 Independent living

The philosophy of Independent Living (IL) originated in California in 1972 (National Advisory Group (NAG) 2005). The IL philosophy promotes a social rather than a medical model of disability where people with a disability have a right to contribute to and participate in society as equals (NAG 2005). In Ireland, the first Centre for Independent Living (CIL) was established in Dublin in 1992 to enable people with a disability achieve independent living (Murphy and Conroy 2006). Currently, there are 22 CILs operating throughout Ireland (Centre for Independent Living 2015).
The key principles of independent living are choice, control, freedom and equality (European Network on Independent Living (ENIL) 2013). According to the ENIL, independent living focuses on empowerment and enabling people with disabilities to have control over their everyday life (ENIL-ECCL 2013). It is important to note that Independent Living does not mean that people with disabilities have to cope in isolation, it means that they have a right to “choice and self-determination within the “wider community”, that they are supported and allowed to participate in society and develop their potential (Murphy and Conroy 2006:17).

In this study, independent living is seen as “the daily demonstration of human rights-based disability policies. Independent Living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in...daily life. Independent Living requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent Living is for all disabled persons, regardless of the level of their support needs” (ENIL-ECCL 2013:40).

A systematic search of the literature was carried out and the resultant review is presented in Chapter 2. In Chapter 3 the methodology for this study is described. The findings are detailed in Chapter 4 and Chapter 5 includes the discussion of the findings in the context of the literature. Finally Chapter 6 includes the conclusions, recommendations and limitations of the study.
CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

As stated briefly in Chapter 1, the aim of this study was to further investigate the factors which impede people with muscular dystrophy (MD) from living independently. Therefore the key concepts were (i) MD and (ii) independent living and a systematic search of the literature ensued. In order to achieve this, an exhaustive list of search terms were used and these are detailed in Appendix 1. The following databases were searched: PubMed, CINAHL, PsycINFO, ProQuest Nursing & Allied Health, British Nursing Index and Medline, from 2005-present. Only literature that was peer reviewed and in the English language was included and a more detailed account is available in Appendix 2. The systematic search of the literature generated 21 articles (Appendix 3) on which the literature review in this chapter is based.

This chapter begins with literature on muscular dystrophy and independent living (2.2) and is followed by a section on the supports for independent living (2.3). The literature describes the nature of those supports: social and personal support (2.3.1), practical support (2.3.2), medical support (2.3.3) and financial support (2.3.4). Finally this chapter ends with some conclusions (2.4).

2.2 Muscular dystrophy and independent living

With developments in medicine and technology, people with MD have a longer life-expectancy, however, the disease will still progress, and individuals will require higher levels of assistance over time (Gibson et al. 2007; Fujiwara et al. 2009). They will experience increasingly more limitations in their daily lives (Munn 2010; Cup et al. 2011) limiting their “day-to-day” choices and therefore becoming more dependent on others to assist them with the activities of daily living (Abbott and Carpenter 2014:1199). The aggressive and multi-systemic nature of MD means that the condition has a huge impact on the individual’s physical and psychological health and general well-being (Kierkegaard et al. 2011; Abbott and Carpenter 2014; MDI 2014a). A recent study conducted by MDI (2014a) indicated that neuromuscular conditions have a considerable impact on several areas of peoples’ lives, including physical well-being, financial resources, family life, social life and mental health. Over two thirds (69%) of participants stated that their condition had a ‘very big’ or ‘big’ impact on their independence (MDI 2014a).

The concept of independent living among people with MD is reported in numerous ways in the literature. In their study on Duchenne MD and home mechanical ventilation, Dreyer and colleagues coined the phrase “independent dependency” (2010b:6). This refers to the
idea that although the young men in the study acknowledged their dependence on others for most aspects of their daily living, they still felt they lived active independent lives. Participants felt they had a say in how the help and support they required was given, and were involved in decision-making around their condition. Others have reported on the significance of decision-making. A study of Japanese men with DMD stated that participants in their study indicated a “self-reliant independency” which they displayed by choosing to move from institutionalised care into the community (Yamaguchi and Suzuki 2013:4). This was a significant decision to make as traditionally in Japan, people with MD live in sanatoria as opposed to the home or the community. The men chose to accept a lower level of support because they wanted more autonomy in their daily lives and wanted to take ‘responsibility’ for their lives (Yamaguchi and Suzuki 2013:4). Gibson et al. (2007) found that two participants in their study of n=10 held very different views on the term “independent living”. One “embraced” the term and debated about the extent to which social services facilitated him in doing this, while another saw himself the same as any other person who lives alone, feeling that no distinction between disabled or able-bodied should be required (Gibson et al. 2007: 513).

There is no data available on the number of disabled people that could be classified as ‘living independently’ in Ireland. The Central Statistics Office (CSO) captures data on ‘person’s living alone’ and in 2011, 106,270 people with a disability (17.9% of all disabled people) were classified as living alone (CSO 2012). Of these, 54,914 were classified as having a condition limiting basic physical activities (CSO 2012). For those who may wish to gain an insight into the experience of living independently, Muscular Dystrophy Ireland’s “Home from Home” apartment offers people with MD this opportunity (MDI 2014b). In 2014 several voluntary groups utilised the apartments and for some of them this was their first experience of living outside their homes. Enabling people with MD to live independently allows them to live more autonomous lives and to be key decision-makers with regard to their condition. It also supports equality of opportunity.

2.3 Supports for independent living
In order to live independently, there are several kinds of supports that people with MD require; social and personal support, practical support, financial support and medical support.

2.3.1 Social and personal support
Many studies report on the loneliness, social isolation or marginalisation that people with MD experience in their daily lives (Gibson et al. 2007; Dreyer et al. 2010b; Chen et al. 2013). Gibson et al. (2007:514) found that people with MD held low expectations with regard to
how they were treated and viewed this as both normal and troubling. Chen et al. (2013:7) refer to the “social dimension” of MD, where individuals reported feelings of embarrassment about their illness and experiences of being stigmatised due to their condition. In a study aimed at describing function and disability in adults with MD, findings showed that restrictions in social and lifestyle activities were experienced (Kierkegaard et al. 2011). Others have reported obstacles to social participation which include having “no power, no pep, no guts” indicating their possible lack of energy and motivation (Cup et al. 2011:4). This is not the case for all people with MD, with many experiencing satisfaction with their leisure and recreation activities (Kierkegaard et al. 2009).

For people with MD, the importance of being able to leave the house and participate socially in the community is noted in the literature. For some people with MD being “out of the house” was viewed as hugely important to their overall well-being allowing them “time alone” (Gibson et al. 2007:509). Being able to go outside the home, however, requires a great deal of planning and effort on the part of friends and carers. In one study, participants reported postponing or avoiding activities like shopping, sport or going out as their limitations increased (Cup et al. 2011). In order to enable people with MD to have the social outlets that they deserve, requires a great deal of personal support from family, friends and personal assistants (PAs).

Personal assistance is viewed as a key element in allowing people with disabilities to “exercise their right to independent living” (ENIL-ECCCL 2014:7). CILs, Enable Ireland and the Irish Wheelchair Association are administrators of PA services in Ireland and the service is funded through the Health Service Executive (HSE) and community employment (CE) schemes (ENIL 2013). MDI (2014a) found that over two-thirds (68%) of their members required assistance from a family member. This finding mirrors others, for example, Chen et al. (2013) who found that the extended family played a key role in providing support and Wee and Lysaght (2009) reported that family and friends were viewed as one of the influential factors in participating in activities. Indeed, in one study interviewees with MD who were making key transitions in life, for example, moving to college or training or leaving the family home, reported feeling that no one outside their family really cared about them (Abbott and Carpenter 2014).

The support received from those outside the family, PAs and the State, varies from country to country. In a recent study of MDI members, only one fifth (20%) of respondents indicated that they had access to paid assistance and a further 22 per cent needed assistance but could not gain access (MDI 2014a). Need alone does not result in the provision of the service, but a great deal of campaigning and petitioning is also required (Buchanan 2014). A recent report indicated that while funding in the area has increased since 2009 this has
been concentrated on the provision of home-care rather than the provision of support for independent living (Buchanan 2014). In Japan the majority of people with MD choose to live in institutions where they receive round-the-clock-care as there are no systems in place to provide care in the home. On the other hand, Danish people with DMD are provided with 24-hour personal assistance in their home which is paid for by the State (Dreyer et al. 2010b). They also receive support with education where necessary and are offered life-long ventilator support at home (Dreyer et al. 2010b). The level and quality of care also depends on the financial circumstances of individual families and the government (Doi 2010 in Yamaguchi and Suzuki 2009). Furthermore, the type of assistance offered to people with MD needs to be the “right” kind of help, people who can “cope” with the high level of dependency yet enabling independent living (Dreyer et al. 2010b: 7). The relationship between PAs and people with a disability can be complex as a variety of tasks have to be undertaken depending on the level of dependence, and often service-users have little control over the level of input they have in the service (Buchanan 2014). However, the service is invaluable to people with disabilities and has been linked to a better quality of life and with facilitating social inclusion (MDI 2009; Buchanan 2014).

2.3.2 Practical support

Along with personal and social support, people with MD require various levels of practical support in order to carry out the activities of daily living. Practical support includes the use of specialised equipment and assistive devices as well as environmental issues, such as, home adaptations and changes in the living environment. Equipment and assistive devices required by people with MD include wheelchairs (manual or power assisted), ventilation machines, ceiling and bed hoists, devices for eating, high-low profile beds, shower chairs, stair lifts and others (Gibson et al. 2007; Wee and Lysaght 2009; MDI 2014a). These devices become an integral part of daily living and in some cases are even considered “embodied extensions” of the person, they are not consciously considered (Gibson et al. 2007). Having access to these practical supports is crucial in determining the level of activity among people with MD. Several studies have identified key factors in participation, which include physical accessibility and supports in the form of aids, wheelchairs and other home equipment (Kierkegaard et al. 2009; Wee and Lysaght 2009).

Assisted ventilation is required by many people with MD and can include invasive or non-invasive ventilation (Dreyer et al. 2010b). In a study on life for people with MD living with home mechanical ventilation (HMV), researchers reported that participants believed the ventilator gave them “security” and “did not restrict their activity any more than a wheelchair”, they were satisfied with their decision to opt for this equipment (Dreyer et al. 2010a). In Ireland people with MD, who require assisted ventilation, use the BiPAP machine (non-invasive) and there are often delays in accessing these machines. This is worrying as
HMV has been shown to extend the lifespan of people with MD (Dreyer et al. 2010b) and without the machine they have a higher risk of developing respiratory infections (MDI 2014a).

Delays in accessing the equipment required to assist with the activities of daily living has been reported in several studies (Henschke 2012; MDI 2014a). These problems have been linked in part to long approval processes and onerous bureaucratic procedures (Henschke 2012). In Ireland four in 10 people with MD reported delays in accessing equipment, particularly with regard to wheelchairs, with one person having to wait for over a year for a new wheelchair (MDI 2014a).

Home adaptations are required by many people with MD, particularly as the condition progresses. In Ireland, over half of people with neuromuscular conditions (57%) had made adaptations to their house (MDI 2014a) while other studies reported four in ten having done so (Kierkegaard et al. 2009). While grants are available, often they do not cover the full cost so in many cases the cost of home adaptations are borne in part or full by the family, placing a financial burden on them (Kierkegaard et al. 2009; Henschke 2012; MDI 2014a). Assistive devices and home adaptations not only allow people with disabilities to live more independently but in the longer term, they can also provide savings to healthcare and social care budgets (National Disability Authority 2010). However, delays and the level of bureaucracy surrounding their acquisition impacts on an individual’s capacity to live independently.

2.3.3 Medical support
While there is no cure for people with MD, it has been suggested that management of the condition, by a multi-disciplinary team, can help to support independence (Baker 2014) and improve quality of life (MDI 2014a). There are many potential specialists for example, neurologists, dieticians, cardiologists, psychologists, and not all people with MD will need to see all of them. However, most people with MD could benefit from physiotherapy and occupational therapy (MDI 2014a). In the USA in 2010, over half (57%) of people with Friedreich’s Ataxia MD saw a physiotherapist at least once or twice a year and in Canada during the same period, a similar percentage (59%) reported doing so (Polek 2013). In Ireland in 2014, the figures are much smaller with approximately only one third of people with neuromuscular conditions (31%) seeing a physiotherapist in a clinic at least annually (MDI 2014a).

Several studies have reported on the perceived benefits and effects of various kinds of exercise and training for people with MD (Fregonezi et al. 2005; Rassler et al. 2007; Aldehag 2013). Rassler et al. (2007) assessed the training effects of home-based respiratory muscle
endurance training on patients with mild to moderate myasthenia gravis and found that while the results pre and post training did not vary significantly, there were changes in the perceived level of physical fitness. Participants felt better and many stated that they would repeat the training programme. Fregonezi et al. (2005) also assessed the effects of a breathing training programme, combined with inspiratory muscle training in people with myasthenia gravis and found an increase in respiratory strength and endurance amongst participants. A study examining the effects of a hand-training programme with participants with MD reported that while the drop-out rate was high (28.5%) the programme appeared to have an impact on performance of and satisfaction with the activities of daily living (Aldehag et al. 2012). These studies suggest that varied programmes and interventions could be helpful in enabling people with MD to obtain a better quality of life and live more independently. Barfield and Malone (2013) believe that lack of exercise is a risk factor for secondary conditions among people with disabilities, including MD. In their study on the benefits of exercise among wheelchair soccer players they found that people with MD cited social interaction as the primary benefit of exercise (Barfield and Malone 2013). The psychological benefits of physical activity have also been identified, with one study indicating that higher levels of physical activity resulted in lower levels of self-reported depression (Rosenberg 2013). Being supported in pursuing physical activity can improve people’s physical and mental health and enable them to live independently should they choose to do so.

2.3.4 Financial support

Conditions such as DMD bear a “considerable economic burden” for the families affected (Landfeldt et al. 2014). In the UK in 2012, the total average per-patient annual cost (in US dollars) of DMD was estimated to be $118,980 with over one quarter (27%) being spent on nonmedical community services (Landfeldt et al. 2014). This estimate included hospital admissions, medical appointments, medications and tests, community services and aids and devices. Other countries range in per-patient cost from $80,120 (Italy) to $120,910 (USA). There is no such data available for Ireland. However, the HSE had a non-capital expenditure of €1.5m on care for people with disabilities in 2013, a reduction of 1.2 per cent on the previous year (Department of Health 2014).

Recent data from the CSO indicate that only 14 per cent of the population aged 15 years and over with a condition that “substantially limits one or more basic physical activities”, participate in the labour force (CSO 2012). Lack of participation in the labour force impacts on individuals’ capacity to provide financially for their daily living and can lead to an “increased risk of poverty and material deprivation” (Economic and Social Research Institute 2015:5). In Ireland the number of adults with neuromuscular conditions, who are unemployed, is more than three times the current national average - 38% vs. 11.5% (MDI
Over one third (37%) were in receipt of the Disability Allowance or other form of social welfare payment, for example, Domiciliary Care Allowance, Mobility Allowance and Invalidity Pension (MDI 2014a). The key barriers to employment include lack of flexibility regarding part-time and full-time work, inaccessible buildings, lack of support as well as the perceived negative attitude of employers towards disability (Abbott and Carpenter 2014; MDI 2014a; ESRI 2015). Several studies have highlighted the challenges faced by people with MD who are seeking employment. The physical limitations of the condition mean that full-time stressful positions are not open to them. However, data indicates that there is a high level of ‘labour market orientation’ among people with a disability with over half indicating that they would be interested in work if the circumstances were right (ESRI 2015:39). What are required are part-time flexible positions where the needs of people with a disability can be accommodated. Chen et al. (2013) reported that even though eight of the nine people in their study were employed in some capacity, they struggled with fatigue and obtaining sick leave, so throughout their working lives, some had lost their jobs and struggled to find new positions. Abbott and Carpenter (2014) found that one third of the young men in their study (average age 19.6 years) were neither in education, training or employment. In addition, those in full-time education questioned this option, indicating that the only alternative was “a day centre” (Abbott and Carpenter 2014:1196). They felt their choices were limited.

Having access to adequate finances to support independent living is a challenge faced by most people with MD and impacts on access to assistive technology and personal assistance (Wee and Lysaght 2009; Henschke 2012). The study carried out by MDI indicates that almost two thirds (64%) of participants felt their condition had a ‘very big’ or ‘big’ impact on their financial resources (2014a: 6). Wee and Lysaght (2009:1640) highlighted the fact that participants in their study, who required 24-hour care, were able to live in the community because they had access to financial support which enabled them to “direct their own care and hire personal attendants”. This option is limited in Ireland. People with neuromuscular conditions in Ireland rely heavily on social welfare benefits and often experience difficulties and delays in obtaining entitlements (MDI 2014a).

2.4 Conclusion
The Independent Living (IL) philosophy promotes a social rather than a medical model of disability; it fosters an empowerment and enabling philosophy whereby the choices and decisions of people with disabilities are supported. Advocates of IL recognise the right of people with disabilities to participate in society and develop their potential. MD is a condition that impacts hugely on individuals’ physical and psychological health and general well-being (Kierkegaard et al. 2011; Abbott and Carpenter 2014; MDI 2014a). To enable
people with MD to live independently, access to technical aids, personal assistance and/or community services are necessary (ENIL-ECCL 2013).

For people with MD, being able to participate fully in society is a fundamental right and to do this requires a great deal of personal support from family, friends and PAs. The support received from those outside the family, varies from country to country and often the level and quality of care can depend on the financial circumstances of individual families and governments (Doi 2010 in Yamaguchi and Suzuki 2009). In addition, practical support such as specialised equipment and assistive devices as well as environmental issues, play a key role in enabling independent living.

Conditions such as MD place a considerable economic burden on those with the condition. Having access to adequate finances to support independent living is a challenge faced by most people with MD and affects access to assistive technology and personal assistance (Wee and Lysaght 2009; Henschke 2012). Many with the condition are unemployed or not in training or education programmes which impacts on their capacity to provide financially for day-to-day living. Key barriers, for example, lack of flexibility regarding part-time and full-time work, accessible buildings, lack of support as well as the perceived negative attitude of employers towards disability have been identified (Abbott and Carpenter 2014; MDI 2014a; ESRI 2015). While there is no cure for people with neuromuscular conditions, the management of the condition, by a multidisciplinary team can help to support independence (Baker 2014) and improve quality of life (MDI 2014a). Being supported in pursuing physical activity can improve people’s physical and mental health and enable them to live independently. Access to adequate social, personal, practical, financial and medical support should be provided for people with MD to enable them to live independent lives, should they choose to do so.
CHAPTER 3 METHODOLOGY

3.1 Introduction
This chapter outlines the methodology employed in this descriptive qualitative study. It outlines the aims and objectives, recruitment of the sample, inclusion and exclusion criteria, ethical approval, method of data collection, data analysis, participants’ biographical data and limitations.

3.2 Aim and objectives
The aim of this study was to investigate issues that impede individuals with MD from independent living.

The key objectives of the study were to explore the issues which impede individuals with MD from independent living in terms of:
- assistance and support
- supporting and managing health
- the physical environment
- education, employment and further training
- financial implications

3.3 Recruitment of the sample
The study employed a qualitative research methodology. The sample for this study included adult persons with MD encompassing all genetically determined muscle wasting conditions. A purposive non-probability sample of (n=31) were recruited via Muscular Dystrophy Ireland (MDI) who acted as the gatekeeper for this study. Members of MDI were chosen as potential participants because of their knowledge and lived experiences of the study topic (Rabiee 2004). MDI advertised the study via its website, social media links, conferences and staff also assisted in recruitment. Potential participants were provided with a letter of invitation (Appendix 4) and an information leaflet on the study (Appendix 5) by the gatekeeper prior to giving their consent to participate.

3.4 Inclusion and exclusion criteria
3.4.1 Inclusion criteria
Adult persons (over the age of 18 years) with MD encompassing all genetically determined muscle wasting conditions.
3.4.2 Exclusion criteria
Adult persons with MD encompassing all genetically determined muscle wasting conditions who having received the study’s information, declined to participate.

3.5 Ethical approval
Ethical approval was obtained from the School of Nursing and Midwifery Research Ethics Committee, Trinity College Dublin. The study adhered to the principles of good ethical practice in research as identified by the International Council of Nurses (2006). Confidentiality was assured and to protect participant identities, pseudonyms were used in the focus group interviews, so that any identifiers from the focus groups would not appear in any report, publication or presentation. Participants volunteered to take part in this study and were free to withdraw at any time without penalty. All participants gave written consent (Appendix 6) and completed a biographical questionnaire (Appendix 7) prior to their participation in the study. With participants’ permission interviews were audio recorded and all study data were stored in a secure location and access to raw data was restricted to the research team.

3.6 Data collection
Data collection was underpinned by Curtis and Tracey (2014) methodology and consisted of four focus groups with people with MD. In planning these, the research team and the gatekeeper took into account setting characteristics including the type of building facility and its accessibility to maximise mobility, furnishings, disruptive background noise, transportation and personal assistance which were all considered in the planning of the focus group interviews (Kroll et al. 2007). This method of data collection was chosen because it facilitates the collection of data from the person as an individual and also from the person as part of a larger group (Massey 2011). Key to this process is participant interaction (Gill et al. 2008) as it is the interaction between participants that helps to clarify similarities and differences about the topic under discussion (Freeman 2006). Key to successful interaction is providing participants with a safe environment for self-disclosure (Krueger 1994) which is achieved by selecting participants on the bases of applicability (Rabiee 2004), sensitive questioning from the moderator and prior establishment of ground rules (Krueger 1994). All groups were facilitated by the same moderator with the assistance of another member of the research team (Kirchberger et al. 2010).

A purposive sample of adults with MD were recruited via the gatekeeper, (n=4) focus group interviews were conducted in three different locations and regions across the country. A semi-structured interview guide was employed, the guide was used to create a balance between the focus of the study and each interview’s discussion (Curtis and Tracey 2014)
and collected data on three main areas: (i) What kind of supports do you think are essential to enable persons with MD to live independently? (ii) How does your condition impact on you financially? and (iii) any other comments (Appendix 8). This guide was also used as the analytical foundation in this study (Massey 2011). The concepts of validity and reliability were applied to the planning, conduction and analysis of the focus groups (Jayasekara 2012). Once each focus group’s data collection was complete, the other research team member began the feedback and verification loop by giving participants an overview of the contents of their discussion, thus offering them the opportunity to give feedback and confirm each group’s conclusions (Webb and Kevern 2001; Massey 2011).

### 3.7 Data analysis

The resultant biographical data were analysed using simple descriptive statistics on MS Excel. A qualitative approach was applied in the analysis of the focus groups and was conducted using a combination of data analytical approaches in the simple thematic analysis of the data (Halcomb and Davidson 2006; Massey 2011).

### 3.8 Participants’ biographical data

The biographical data of the (n=31) participants included (n=16) females (52%) and (n=15) males (48%). Participants’ mean age was 44 years and ranged from 18-67 years. Twenty-nine of the 31 participants replied to the question on area of residence and of these, city was the majority (n=14; 48%), followed by town (6; 21%), rural (5; 17%) and village (4; 14%) dwellers. Participants were asked what their highest level of education was, 28 of the 31 participants replied. Most participants (n=14; 50%) were educated to second level standard, six people had completed vocational training and five people had a third level education; three had undergraduate degrees and two had postgraduate degrees. One person was self-educated and two had primary level education (Figure 3.1).

![Figure 3.1 Highest level of education](image)
Participants’ responses (n=28) to employment status are represented in Table 3.1. Most participants were unemployed (n=12; 43%), five were retired (18%), four were either employed part-time or were a homemaker (14%), two were students (7%), one was self-employed and no participant was employed on a full-time basis.

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<td>Unemployed</td>
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<td>Retired</td>
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<td>Employed part-time</td>
<td>4</td>
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<td>A homemaker</td>
<td>4</td>
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<tr>
<td>A student</td>
<td>2</td>
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<td>Self-employed</td>
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<td>Employed full-time</td>
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*Table 3.1 Employment status*

When asked to categorise their current living arrangements, the largest number of participants were living on their own (n=9; 31%). This was closely followed by those living with parents (n=8; 28%). Four people lived with either their partner/spouse and children, or lived with children alone (n=4; 14%). Three people lived with a partner/spouse (n=3; 10%) and lastly, one person lived with a friend (n=1; 3%).

*Figure 3.2 Current living status*
3.9 Limitations of the study

The sample was limited to adult persons with MD encompassing all genetically determined muscle wasting conditions. The sample was recruited by MDI who acted as gatekeeper. All participants were self-selected in that they chose to take part in the study and therefore findings reflect their views only.
CHAPTER 4 FINDINGS

4.1 Introduction

The aim of this follow-up descriptive qualitative study was to further investigate the issues that impede individuals with MD from independent living in terms of: assistance and support, supporting and managing health, the physical environment, education, employment and further training and financial implications. This chapter presents the findings from n=31 participants from four focus group interviews. Findings are presented under the following headings: assistance and support, supporting and managing health, assistive equipment, physical environment, education, employment and further training, financial implications and voicing for change.

4.2 Assistance and support

4.2.1 The personnel who assist and support people with MD

While the study identified participants were in receipt of three kinds of assistance and support, which included support from personal assistants (PAs), Home Help and carers, it also identified that some participants did not have any assistance. Participants held different interpretations on the function of these roles particularly in relation to PA and Home Help.

Some participants were in receipt of PA services and generally it was held by those participants that a PA is employed by a person with MD (the Leader) who considered PAs as key personnel who facilitate independent living. Other participants were in receipt of Home Help and explained Home Help services are provided following assessment by the Health Service Executive (HSE) and other agencies. The Home Help services involve carrying out various personal and domestic errands for a person for set periods of time, for example 1 hour per day. Participants reported that there is a defined list of tasks which HSE Home Help can/cannot do, whereas they felt that Home Help provided by agencies do not have the same limitations and in general, participants were more satisfied with the agency services. Other participants’ support was provided by carers who were either, formal carers that is paid the Carer’s Allowance or unofficial carers, most often family members who were not receiving any form of payment.

Other participants did not have any experience of any form of care or help and explained that they were physically trapped and they felt completely isolated; “there was a period in my life before I was married when I didn’t have any type of help at all for a year and I think that it was the most difficult period in my entire life ... it was extremely difficult to have a condition where you just existed rather than lived” (#11). While for some participants...
dependence is implied when assistance and support such as Home Help and carers are involved, which is in contrast to that of the PA service. However all participants agreed that not having any access to care and support was detrimental to their well-being irrespective of who was providing the care.

4.2.2 Personal assistants

The PA service is essential for people with disabilities to enable them live independently and participate fully in society (Buchanan 2014).

4.2.2.1 The PA role

The role of the PA according to participants is to enable the person with MD to achieve their full potential. The PA role consists of looking after the person’s personal care, undertaking physical tasks and enabling the person to achieve their full potential; for example, getting employment and if in employment, assisting them. Participants emphasised that “the key word is ‘personal’ because the services of the PA are personal to me ... my PA is the personal extension of my limbs ... I am in control” (#22). Some PAs also do some domestic work but this is not their principal role. The PA’s insurance covers them to drive the person with MD’s car and they travel with the person at all times; “the two key words are ‘choice’ and ‘control’” (#22).

4.2.2.2 Eligibility

Participants reported that it is difficult to get information about the PA’s role and to determine what the eligibility criteria are to acquire a PA and asked if they were ‘bad enough’ to justify having a PA. Some participants thought that living alone was a requirement, “someone from the HSE said this to me: ‘if your daughter lives with you, you don’t need anyone’” (#13). Others agreed that it should be irrelevant who one lives with or where one lives, but that it was how one lives is key, and, with the assistance of a PA, one can live independently in an environment along with others.

Timing and flexibility were two issues that were reported regarding accessing a PA. A PA might be required at short notice should one’s circumstances change. This point was illustrated by one participant who described how after a fall, their status changed from independence to dependence. Considering that MD is a progressive condition, participants worried about their ability to access a PA if/when they needed one in the future; “you say at what point will I feel I need a PA and will there be one available if I do [need one] or how do I go about getting a PA” (#1). For those who already have a PA, they were concerned whether their PA hours would be increased to meet their growing needs as their condition progresses.
4.2.2.3 Application process and funding

There was confusion and a general lack of knowledge about the application process for a PA; “in some areas of the country you apply from the Centre of Independent Living but in other parts of the country, you might apply to another organisation but I think that it would be better if there was only one [organisation]” (#4). For participants who had a PA they explained that the Family Support Worker is the first person to contact but others mentioned that there are various service providers involved and that there is no specific contact number. HSE funding needs to be secured and the Irish Wheelchair Association or Centres of Independent Living act as brokers on the HSE’s behalf. Some of the negatives were that the assessment process is perceived as arduous: “people are put off by going through all that” (#9) and another participant stated “I made an application a few times but then I gave up because it was like hitting my head off the wall” (#10). The person with MD is interviewed by a panel to determine their needs and eligibility, and participants felt that one’s success can often depend on how articulate one is. If approved, participants agreed that it would be much more satisfactory to have the person with MD involved in the recruitment of their own PA, rather than an organisation recruiting/interviewing potential PAs on the person’s behalf, when there is an increased risk of misinformation. Though there was some variation around the country, it was deemed more difficult to get a PA if one lives at home and it was considered irrational to be reassessed on an annual basis considering that MD is a chronic condition. Some participants felt that it was easier to secure a PA if one was an urban dweller; “no clear, defined route. Geographically there’s a huge issue as if you live in Dublin, you have a much better chance of getting some sort of service than living in rural Ireland” (#3). As the funding is limited for acquiring a PA, some participants self-fund additional help to carry out domestic tasks and assist with their work, which has a knock-on financial impact.

4.3 Supporting and managing health

4.3.1 Health professionals

Health professionals’ knowledge-levels and abilities were found to be variable regarding MD; “a lot has to do with the individual and depends on how interested they are in your condition” (#22). Many participants who were not in receipt of State support expressed that they expected some level of expertise when they pay for GP and consultant appointments; “it’s very frustrating if you have to pay a specialist €150-200 and you are still not getting an answer. My specialist turned around to me and said ‘you’re my only live patient’ and needless to say, I didn’t go back to [them]” (#23). Many people self-fund appointments to access specific health professionals, because the public health waiting lists are prohibitively long and otherwise their health suffers; “the GP referred me and it took a year for me to get diagnosed by a neurologist” (#5) and also “from referral it took 18 months on the waiting list to see the consultant” (#6). Similarly the wait times to acquire diagnostic...
tests are often up to 12 months which participants felt were unacceptable considering the stress and worry that is endured in the interim. Many participants had experienced the following sequence of events: at the time the neurologist made a diagnosis, participants were not linked to any service, they were not given any leaflets or any other information about accessing appropriate medical care, support and entitlements; “at time of diagnosis you are told nothing you have to find out everything yourself” (#5) and “when I went to the neurologist and [they] told me that I have a rare condition I was just left... I wasn’t told a thing how I’d cope. I was told I have a condition which I had never heard of and other people [I know] had never heard of it and I was just left. The neurologist never told me or linked me into any system or said ‘now you’d want to get in contact with this organisation or that organisation’. I just sat at home myself and wondered, because nobody I know had heard of it, and I didn’t get a leaflet or anything and I just had no-where to turn. And I live on my own and so it was very devastating to suddenly find yourself with a condition that no one had heard of...” (#6). A number of people had a more positive experience; “I was diagnosed by a neurologist in [x] and [x] was superb. [They] said this is the Foundation in the States and you have to register with them and there is a Professor in the UK and [x] is a leading researcher in the area. [X] said that the most important thing is to stay positive and [x] said ‘I will see you in 6 months’” (#1).

Participants praised the multidisciplinary teams and services provided by the specialist MD clinics. The key health professionals in participants’ lives were the GPs, physiotherapists, occupational therapists and Public Health Nurses - though as stated earlier, their knowledge levels about MD was variable; “some [health professionals] are intimidated by the condition and feel out of their depth and want to get away” (#9). GPs were most valued and participants considered them the most important health professional and the best source of information; “my GP is excellent and [x] will follow up and [x] will call, but at €55 a visit, I try to hold back until I really need to ... I know [x] is good and I know [x] will research and follow up ... but it’s expensive” (#23) and “definitely my GP is wonderful but the local Public Health Nurse is great as well” (#25). GPs who were interested in learning more about MD listened to, and were open to learning from their patients. Generally participants have 6 monthly appointments with their specialist but if such appointments are needed more urgently participants need to be referred on by their GP; who was considered instrumental in trying to efficiently refer the person as speedily as possible.

Physiotherapists and occupational therapists were also valued and their input is needed regularly but there are challenges with accessing them; “I have a great community OT and physio but a lot depends on where you live ... you still have to fight for it” (#17). When possible, participants preferred to be visited by the community physiotherapists because visiting the physiotherapist in an HSE centre is physically challenging and when transport
has to be paid for, it has a knock-on financial impact. Access to the community physiotherapist (referred by GPs) varies with geographical area. For example some participants who were living in the city were visited by the community physiotherapists whereas people living further away had to travel to the physiotherapist in a HSE centre which imposed further challenges on participants: travel and its subsequent cost.

To improve services, one suggestion was that health professionals need to be educated about the role of PAs; “doctors need to be constantly reminded of the difference between a PA and a carer” (#2) and how they need to be involved at every level of the person’s care; “you still need the assistance of a PA if you are in hospital, so there is a need for a bit of education for staff in hospitals about this so they understand the need for the PA” (#2). One participant explained that some people with MD were fearful that they could lose their PA service if they had to go to hospital; “people have lost their PA because they had to go into hospital for a few weeks, so it is so important to maintain the PA service when in hospital because staff don’t have the time … this really needs to looked at” (#22).

The knock-on impact on participants of not being able access medical care was that their health and (as a consequence) their independence was affected. When participants could not access the care they needed, they had to rest more, they were in more pain and they were curtailed in what they could do.

4.3.2 Health-related entitlements
The study sought participants’ views on state provisions such as benefits and entitlements; for example, the Long-Term Illness Scheme, the drug payment scheme and medical cards, and also identified that some medications or procedures are not covered under those schemes.

4.3.2.1 Long-Term Illness Scheme
The most striking and consistent finding across all four focus groups was the lack of awareness of the Long-Term Illness Scheme and that MD is one of the conditions listed in this scheme; “heard about it but there is a lack of information” (#11) and “there is a lack of communication regarding entitlements” (#12) and “the long-term illness card is not well advertised by the HSE” (#2) and “no one tells you what you are entitled to, you have to find out for yourself” (#5). This lack of knowledge most likely explains the very low uptake of 32% reported in MDI’s National Survey (MDI 2014a). Of those who had heard of the Long-Term Illness Scheme, there was much confusion about what was covered and the application process. A small number of participants who were part of the Long-Term Illness Scheme appreciated the fact that the scheme was not means tested but highlighted some inadequacies. The scheme does not include all forms of MD, equipment is not covered and
there are a limited number of medications covered; “they don’t consider an aid or an appliance as important as a drug but if it’s a form of therapy, it should be included on the Long-Term Illness Scheme” (#17). A few participants explained that their Consultant had written a letter to justify the inclusion of a particular medication (which was not otherwise included) and as a consequence, the medication was then added/covered by the Scheme. Participants agreed that as their condition progresses, all new treatments admitted to the Scheme requires separate approval by the HSE and Department of Health, and this process is onerous; “if the doctor wants to change a medication you have to go through the whole rigmarole of getting it approved” (#23) and “I can’t understand why if it’s confirmed that you have a disability, why you have to be reassessed every year, especially when it’s a long-term condition” (#33).

4.3.2.2 Medical card
All participants were aware of the medical card which is means tested and covers all medications and related equipment. Those participants in receipt of the medical card still pay a subscription charge of €2.50 for each medication which can still be expensive, as most participants were taking multiple medications for their condition. Participants who are not eligible for a medical card or not subscribed to the Long-Term Illness Scheme, have to self-fund the cost of all prescriptions which impacts on them financially, and some participants admitted that were not taking all of their medications as the cost was prohibitive and their health was suffering as a consequence. Participants recommended that all people with MD should be offered the medical card.

4.3.3 Other health-related issues
A number of participants highlighted the importance of being prescribed branded medications rather than generic versions (preferred by HSE, Department of Health), as otherwise from participants’ perspectives, potentially life-threatening side effects are possible. In one case, the medication the participant was prescribed was only available/stocked in Dublin and not available nationwide. This was considered inequitable and posed another challenge as a family member had to travel to Dublin to get the prescription.

The full cost of diagnostic tests is not always covered by the HSE or most private health insurers, and hence this poses an added financial burden on people with MD.
4.4 Assistive equipment

“I just don’t know where to turn for any kind of information as regards appliances. I feel there must be things out there that can assist me but where do you find out about them?” (#6).

While emergency equipment is obtainable from the HSE in a timely manner, participants reported that there are often delays with receiving equipment. The extent of the delay varies across HSE areas and the process of applying for equipment is considered very bureaucratic; “it depends on who you ask and how you ask the question, and how the person you ask, receives it” (#23) and “it is a bureaucratic process when applying for equipment. There is a lack of communication and passing the buck between departments” (#14). Some specialised medical equipment cannot be purchased but instead is rented from private companies where the rental cost is paid for by either the HSE (if the person has a medical card) or self-funded. Some participants queried the appropriateness of this and would like the option of owning their medical equipment considering the chronic nature of MD; “it’s a complete and utter waste of money by the HSE … need to have an option to buy it after a certain period of rental and it should then come with a service agreement” (#9).

Many of the participants who were wheelchair users reiterated many times that their wheelchairs are the key to their independence; “your chair is your legs really, at the end of the day” (#11). Having a second (back-up) manual wheelchair was considered essential if the primary wheelchair broke: otherwise a person “would be confined to bed until [they] would get the chair” (#11) and “I was 1-2 years waiting for equipment, often because parts are not stocked and parts take a long time to order and deliver” (#11). These repairs are cheaper and more speedily completed when done privately whereas participants perceived that going via the HSE process costs more (for the HSE) and takes much longer to complete; “my chair is my biggest problem and getting it repaired. There is no funding to get repairs done and I was waiting for over 12 months to get one fixed. You can’t move without it and everything stops” (#33).

On the subject of personal safety, some participants recommended an emergency response pager for increased personal security and reassurance. Though the installation is free, monitoring is not and participants recommended that this should be free of charge to people with MD.
4.5 Physical environment

4.5.1 The home

Participants reported that when applying for social housing with the aim of living more independently, one has to justify to the local authority why it is needed. For example if the person is living in the family home, they are asked why they would want to move out of home to live elsewhere. Participants agreed that living with one’s family negatively impacts on one’s success at acquiring social housing and as one participant explained; “independent living is not about where you live or who you live with, it’s about a state of mind” (#22).

In relation to housing adaptations, generally the application process was the same: a person’s needs are assessed by an OT (an independent OT not involved in the person’s care) who charges a fee for this assessment. If eligible, a person applies for a grant to fund the approved work from the County Council. OTs were commended for the role they play in the process; “my OT has been nothing but terrific. She came in and interviewed me and got various adaptations completed for me within a month” (#7) and “my OT was brilliant and organised within days, what I needed … anything that makes life a bit easier contributes to living more independently” (#17).

There was some variability with the next steps of the process where in some regions, the County Council pays the applicant directly and then the applicant pays the builder (who they can tender for and choose themselves). In other regions, the grant money was issued only when all work was completed in full and signed off by an assessor. One of the negatives is that the application process for house adaptation can be very bureaucratic; “there should be some clear pathway to get the information and get things done because though [housing adaptation] has been approved, there is so much red tape that makes life so difficult” (#23).

The nature of the work funded by the County Council grant varies across regions and there are considerable differences in how quickly any approved work can be funded and completed. In some regions, if the house adaptation has been completed in one part of the house and is passed, but if another part of the adaptation does not pass, the grant cannot be drawn down until ALL work is completed as there is a single payment process. When grants are not available or approved, any self-funded work imposes a financial burden. Participants recommended that grants need to be flexible to meet peoples’ needs as they may require ongoing adaptations as their condition progresses; “I think that you have to pre-empt what is going to happen [health wise] so that you are ready” (#9). Being able to receive stage payments for completed and approved adaptations would be beneficial to people with MD to assist with financial budgeting.

In relation to adaptations to meet individuals’ needs, participants made the distinction between being disability-friendly versus being wheelchair-friendly. Two participants
described unsuitable adaptations to their homes, which met the requirements for a wheelchair user but were unsuitable for their individual needs (adaptations fulfilled generic standards which did not take the person with MD’s unique needs into account). For example one participant described how the house was designed for a wheelchair user but the participant does not use a wheelchair; “made [the house] accessible for a wheelchair user, but not for me...everything was real low down, whereas I struggle to bend down... and even our back door, it has a step so I have to use the front door” (#15). Another participant stated: “people are designing buildings who are not in wheelchairs and they are getting it all wrong” (#11).  

Suitability of housing and how well it is adapted to a person’s need, directly impacts on a person’s independence. Participants also felt that having adapted their house, they found it more difficult to secure a PA. For those with MD who are offered social housing, there is an even greater requirement to have a PA so both applications should be considered together; “I have heard of people who were offered Council housing but who had to turn it down because they didn’t have access to a PA” (#3).  

4.5.2 Beyond the home

Other issues related to the physical environment include public transport and disability-friendly facilities. Participants described many inadequacies when travelling by public transport. When participants travel by train, often there are no personnel to provide ramps at stations, when seated on the train the next station is not announced and when announcements are made, usually there is not sufficient time given to allow someone with MD to get to the exit door. There are limited designated spaces on buses and a person with a disability often competes with buggies for the allocated space. On a positive note, participants commended the disability-friendly services and facilities available at airports. The physical standard of buildings open to the public is often unsuitable and impractical for people with disabilities, and facilities which are presented as being disability-friendly often do not meet approved standards. For example toilets are often not at ground level and a lift might not be available. Participants reported that even when facilities are accessible to a wheelchair, they are not functional because there is insufficient room to turn a wheelchair; “even to go out in town to meet friends, you have to go to a hotel restaurant that will have a toilet that you can use” (#1). Participants agreed that it is necessary to plan every aspect of their journey in advance, so that if one is going out one needs to consider the route, the quality of the paths and access areas, whether or not disability-friendly facilities and services are available and if not, other alternatives need to be considered.
4.6 Education
There was consensus across all focus groups that participants’ condition directly impacted on their education. Participants spoke about the challenges they faced going through the insufficiently supported Irish educational system; such that some participants felt that they were already at a disadvantage with regard to future/further employment or training opportunities; “I found schooling very hard, I couldn’t carry my bag, I couldn’t get on the bus. I couldn’t go out and play for fear of falling and I can’t get up. And I was very tired. And there was no school in the hospital in those days” (#27). Another participant “had to drop out of [secondary] school because of the disability because there were no supports in the school at that time, though I was still interested in education” (#2). However one younger participant was positive about the support they receive “at the moment I have an SNA in school and if I didn’t have [x] it would be completely different because [x] knows what I need for each class” (#19).

4.7 Employment and further training
There was consensus across all focus groups that participants’ condition directly impacted on (i) their ability to find employment, (ii) the nature of that employment and (iii) the opportunities for further training (some or all of the above applied to all participants). Participants whose condition manifested later in life had to relinquish jobs that they loved and were experts in; “I can’t do the job that I was trained for because I can’t stand for a long time, so it means that there is nothing else that I have been trained to do” (#5). Some participants re-trained but even then found it extremely difficult to get employment. This sequence of events not only impacted on the person with MD but also on their family and their broader network. Participants spoke of the financial and social benefits of working (social integration) and when working, a person contributes to the State and if a PA is employed by the person with MD, the PA is also contributing to the State; “it was counterproductive to cut the PA hours as when they weren’t working, they weren’t paying taxes, so contributing to the workforce and the economy is important for the person with the disability and the State, so everyone wins” (#9).

Generally participants thought that part-time work would be the preferable option to achieve a good quality of life and in one participant’s words: “for your own self mental care and your well-being even for a small amount of money, it’s important to work as long as you can” (#9). Participants maintained that there are many problems with the Community Employment Scheme and that the Disability Allowance does not provide the recipient with financial security to step back into employment. For people with MD who would like to step back into employment or re-train, there was much uncertainty about whether or not their Invalidity Pension would be affected, if they also received the Partial Capacity Payment or
were on the Community Employment Scheme. For participants who are in employment, there are many challenges; “my attainable goals reach out maybe to the end of the week; I wouldn’t plan anything after that because I only know what I can do this week” (#23) and “you are very limited with regards to what you can do compared to what you used to do” (#24) and “the condition changes everything in your life. Even if you are working and do it at your own pace, you could be classed as lazy” (#26). In general, participants preferred to be paid in cash for any part-time work they might do because it is more transparent and there was less chance of jeopardising their current status regarding entitlements.

Under the Disability Act (2005) public sector organisations are to ‘ensure where practicable that 3% of all staff employees are people with disabilities’ but participants questioned if the Public Sector was meeting this target. Many participants spoke of the challenge of getting to work in the absence of transport or a PA; “my big problem is that I have been getting transport to work with MDI and accessible community transport or on occasions taxis but that costs an arm and a leg to go to work, so my big problem is, I am thinking how long more can I continue to avail of this routine and I know IF I could get myself and my chair into the car, I can drive fine” (#1). Another participant stated: “I think the reason that many people with disabilities are not in employment is that supporting services are not available to them. Transport and not having a PA are big issues for people, and also not having an accessible environment, not just the physical environment but the availability of assistive technology” (#22).

4.8 Financial implications

One theme which emerged from all four focus groups was that participants’ condition imposed a financial burden on them, which impacted on all aspects of independent living, “it is twice as expensive to live with a disability because you have to pay for everything to be done, even to hang a picture, you have to pay someone to do it. Everything you do costs money so [one’s condition] does have a huge impact” (#9). One participant said that “I believe that the cost of disability has never been looked at by successive Governments though it’s been brought to their attention” (#11) and another thought that “the money you get given is not enough to live, especially if you have rent and everything else” (#5) though “the mobility allowance helps a lot” (#17).

In relation to assistance and support there were participants who cannot access State funded support and care, they had to self-fund support, care and assistance and this outlay had a direct financial impact on them (4.2). In health-related matters many participants self-funded appointments with health professionals so that they could be seen in a timely manner as the wait lists are prohibitively long (4.3.1). For those who are not part of the Long-Term Illness Scheme or who do not have a medical card (4.3.2), the cost of
prescriptions, diagnostic tests, assistive and medical equipment imposes considerable expense on people with MD (4.3.3 and 4.4); “medications are a big financial burden” (#23).

In relation to participants’ home environment when grants are not available, many people self-fund housing adaptations which impose a financial burden on people with MD (4.5.1). Participants may never be in a position to buy their own home. Not having enough money limits social integration, for example socialising with friends. Therefore participants generally spend a lot of time at home which has a knock-on impact on the cost of living e.g. more fuel is used to heat the house and hence participants have increased energy bills; “I am confined to home so it means that I have the heating going most of the time and that’s a very big expense” (#6) and “we don’t go out, never ... can’t afford it and I am a really cold person and I am always cold ... the heating and things like that are the biggest financial burden” (#7). When at home, participants were more likely to buy ready meals and prepared food (e.g. chopped vegetables) because of their disability; “I don’t cook as I physically am not able to cook so I buy a lot of my meals or ready meals which is expensive” (#12).

Generally participants had reduced opportunities to partake in education, employment and further training as described in sections 4.6 and 4.7. Participants’ condition limited their opportunities to work and the nature of the work they can do. These limitations have a direct impact on participants’ finances.

The cost of transportation was another theme which dominated many participants’ conversations. For participants who can drive, the car is used more so therefore more fuel is used. In some regions some organisations and/or charities provide free transport which participants commended, but there might be many passengers on the same trip so one is dependent on the punctuality of others which is an issue if/when attending a medical appointment. For those participants who are dependent on taxis, they reported that the cost varies considerably between companies and recommended that there should be a standard agreed rate between companies for set distances. This variability can result in a considerable expense to the person with MD and there is additional cost if the person with MD is accompanied by a PA. One participant reported that beginner driving lessons in an adapted car were considerably more expensive than the rates for lessons in a standard car.

4.9 Voicing for change

Participants favoured the direct payment system in the UK where people with MD can choose how best to allocate the money; such as for house adaptations, carers, healthcare etc. Many participants were frustrated by how bureaucratic any application process is and that the services are under-resourced. For example: “my application for the Invalidity
Allowance took six months to process because they are so understaffed so more resources are needed for those services” (#2).

One participant felt that it is impossible to progress any challenge on one’s own so regrettably unless the media is involved, the voices and needs of people with MD are not heard; “if you highlight things in the media then it is on public record and one might get some action… it’s the one thing that Government and politicians will respond to in my experience” (#11).

All participants unanimously agreed that there needs to be a clear pathway from once a diagnosis is made:
“[I] just feel making information available as soon as you are diagnosed with a disability so that you can access whatever you need” (#6).

“Can’t there be an easier way. There is no consistency in the information you get told” (#27).

“Get the information out there. Give us the information and give us a clear path” (#29).

“Just an easier road. It’s already really hard with the disability” (#32).

“I think we need a one stop shop for everything to get clear direction… when you start off, it’s a guessing game… so I’d like to see the one phone number or centre which would be the initial starting point for information” (#22).

“A lot of the [organisational] bodies should talk together, share information and work together. The things we are looking for basic human rights and we wouldn’t be fighting for these things if we didn’t genuinely need them” (#2).
5.1 Introduction

Independent living is a human right as set out in Article 19 of the United Nations Convention of the Rights of Persons with Disabilities (United Nations Enable 2006). “Independent living means all disabled people having the same choice, control and freedom as any other citizen - at home, at work and as members of the community….any practical assistance people need should be based on their own choices and aspirations” (ENIL, Myth Buster Independent Living 2014: 5).

It is in this context that this study explored and identified issues around independent living for people with MD. More specifically, in MDI’s study (2014a) 69% respondents indicated that MD had a ‘very big’ or ‘big’ impact on their independence so this study set out to explore which factors were hindering their ability to living more independently.

5.2 Assistance and support

It emerged from the findings that a range or personnel are involved in the support and care of people with MD and include PAs, Home Help and carers; either formal carers who receive a Carer’s Allowance or unofficial carers who are most often family members. The importance of care and support to those with a disability is evident in the literature (Wee and Lysaght, 2009; Chen et al. 2013; Abbott and Carpenter 2014) and only 20% of respondents to MDI’s national survey (MDI 2014a) had access to paid assistance. In this study some participants were confused about the precise roles and responsibilities of PAs versus those of carers and Home Help personnel. The key features of the PA service versus other services are listed by Buchanan (2014:42) and these include that “people with disabilities select PAs who respect the independent living ethos and are able and willing to work in this way and, leaders decide on the tasks and times of PA service to meet their specific needs”.

The findings in this study demonstrate that participants were unclear about where PA-related information could be sourced, what the eligibility criteria are and how one applies for the PA service (Gibson et al. 2007; Fujiwara et al. 2009; Buchanan 2014). The findings also indicate that access to the PA service in addition to the eligibility criteria, vary geographically. Participants were concerned that the current service is not flexible enough to meet their current needs and worried about being able to acquire increased PA hours in the future when their condition further progresses. These findings mirror those from Buchanan (2014) who interviewed thirty Leaders who had a PA. Interviewees who acquired the PA service more recently were more likely to have less PA hours, and worried about
not being able to retain their current level of service and not being able to increase PA hours if needed (Buchanan 2014).

There was unanimous agreement from participants across all focus groups that there was a need for one organisation to whom all enquiries could be made regarding the PA service and to whom all applications would be submitted. As a consequence, the perceived inequity regarding access to a PA and the varying eligibility criteria in different parts of the country could be eradicated. What is certain from the literature is that the availability of the PA service, which was established to empower people with disabilities to triumph over their daily challenges, is a necessary resource if independent living and an optimum quality of life is to be realised (MDI 2009; Henschke 2012; Buchanan 2014; MDI 2014a). Participants who had a PA confirmed this and explained that autonomy is achievable when one has a PA because all decision-making rests with the person with MD. They reiterated that the emphasis shifts from focussing on basic needs (for example, personal care) to focussing on assisting people with MD to participate fully within their family and the wider community; thus making independent living a reality (Buchanan 2014).

5.3 Supporting and managing health

Maintaining optimum health is key to living independently and to achieve this, a range of health professionals and multidisciplinary teams care for people with MD (Baker 2014; MDI 2014a). In addition, a range of health-related entitlements exist to allow people to manage their health and these go some way towards alleviating the financial burden that people with MD endure.

5.3.1 Health professionals

The participants reported that the health professionals involved in their care had varying levels of knowledge about their condition and suggested that health professionals needed to be skilled up in MD-related issues (Fujino et al. 2015). Participants also suggested that health professionals needed to be made aware of the role of the PA who should be allowed to be present at appointments and in the hospital. The wait lists to access health professionals are extremely long, which was previously confirmed by MDI’s recent study (MDI 2014a). In addition the wait time to access diagnostic tests is unacceptably long, considering the stress and worry that is imposed on the person. Getting access to the appropriate specialist when needed is a challenge for participants, and there is variability regarding access in different geographical locations. Such variability regarding the specialists accessed and the services received, within the same patient cohort has been reported elsewhere (Pandya et al. 2015). On a positive note, participants praised the multidisciplinary teams in the MD clinics. The majority of participants in this study valued their GP most, over all other health professionals, as GPs play a key role in their care for an
extensive period of time, they are pivotal in linking people with appropriate specialists and services and are also a good source of information. Many participants self-funded appointments to speed access to the appropriate health professionals and services. What is clear is that timely access to health professionals and other health-related supports enable people with MD to manage their conditions and live independently (Ravesloot et al. 2005).

5.3.2 Health-related entitlements

Other medical-related issues included the lack of information and communication regarding health-related entitlements. In particular, the Long-Term Illness Scheme is an automatic entitlement for people with MD but only 32% respondents to MDI’s survey reported having one (MDI 2014a). Very few participants in this study were aware of the Long-Term Illness Scheme so its availability needs to be better communicated to the MD population. That health benefits contribute in a positive way to improved health was demonstrated in a randomised trial in the US (Michalopoulos et al. 2012). Even when MDI members are permitted specific entitlements, there are still considerable delays in accessing them and this finding confirms those reported in MDI’s study (MDI 2014a). In an effort to reduce health-related expense, participants suggested that diagnostic tests should be provided free of charge and be included as part of the neurologists’ fees and that all people with MD should receive a medical card.

Improving access to health professionals and all health-related aspects will benefit the health of people with MD and allow them to continue to live independently. Also when health is optimally supported and managed, it reduces the likelihood that people with MD will end up in acute services and thus in the long-term, provides savings to the Irish healthcare system (National Disability Authority 2010, Michalopoulos et al. 2012).

5.4 Assistive equipment

The majority of respondents to MDI’s survey (MDI 2014a) used a wheelchair and many also needed numerous additional assistive equipment for breathing, moving, eating, sleeping, washing and other activities. However 40% respondents reported delays in accessing such necessary equipment (MDI 2014a). Those findings were confirmed in this study where the majority of participants experienced delays in acquiring and repairing assistive equipment. Participants were frustrated because the application process for equipment is very bureaucratic and ‘passing the buck’ between various organisations is common. One participant described their wheelchair as being their legs so the negative impact of having to wait for up to 12 months to have their wheelchair repaired, is considerable and is not acceptable (Sakakibara et al. 2014). Participants explained that some specialised equipment, for example ventilators, is rented from private companies and funded by the
HSE though many participants would prefer to own their equipment considering it is needed for life. What is undisputed from the literature and the findings from this study is that any delays accessing assistive equipment, negatively impacts on peoples’ health, well-being, autonomy and independence (Dreyer et al. 2010b; MDI 2014a; Muenchberger et al. 2015).

5.5 Physical environment

Many people with different forms of MD have challenges with mobility, so having a disability-friendly physical environment is essential both within the home and in public/social areas.

5.5.1 The home

In order for independent living to be realised, a suitable home which is adequate for the person with MD’s needs, is essential. For many people their homes require adaptations and occupational therapists have a key role to play in assessing the person with MD’s requirements and aiding in the application process (Citizen’s Information, 2015). In MDI’s previous study, 57% participants had made adaptations to their home (MDI 2014a) and in this study participants recommended that grants should be flexible to meet peoples’ needs as they may require ongoing adaptations as their condition progresses. Participants favoured either upfront payment or stage-wise payment from the County Council for adaptations, as they are completed. When grants were not available, the costs of adaptations were assumed by the participants and their families, and this finding concurs with other studies (Kierkegaard et al. 2009; Henschke 2012; MDI 2014a). It is imperative that any adaptations are modified to the user’s needs as some participants relayed how adaptations that were carried out on their homes were unsuitable and impractical for them; this unsatisfactory mismatch may go some way to explain why many participants funded their own housing adaptations.

5.5.2 Beyond the home

Botticello et al. (2014) has reported on the importance of having suitable and accessible public environments to facilitate social inclusion for people with a physical disability. Though many public buildings/physical environments claim to be disability-friendly or wheelchair-friendly, they do not meet the required standards as set out by Part M Amendment Regulations and are inaccessible to people with physical disabilities (Department of the Environment, Community & Local Government 2011).

All citizens have a right to travel by public transport but there are many challenges encountered by people with MD when travelling by public transport, so these public
services need to increase their awareness of the requirements of customers travelling with a disability. That challenges of travelling deter people from going out was verified by Cup et al. (2011). This is significant because Ralph and Usher (1995) reported that people with disabilities who live in the community are often already socially isolated. The participants in this study reported that because of the inaccessible and unsuitable physical environment they have to carefully plan their route and determine the suitability and accessibility of the built environment before they leave the house.

5.6 Education, employment and further training

The opportunities for education, employment and further training were curtailed by participants’ condition. In people whose symptoms were present in childhood and who were unsupported in school, their inability to engage with education affected all further opportunities for employment. This finding is borne out in the literature (Fowler et al. 1997).

For people whose symptoms emerged later in life, they had to either relinquish their job and find an alternative job or engage in further training. Depending on the nature of employment, others were able to reduce their hours. Participants’ preference was for part-time work where they could contribute to tax revenues and to the workforce in a meaningful way, while benefitting both financially and socially, and this willingness to work has been reported by the ESRI (2015:39).

However participants were not clear on exactly how their benefits might be affected (jeopardised) when engaged in employment because these benefits are critical to life. Because peoples’ conditions were already imposing a financial burden on them, some claimed that it would actually cost them money to return to the workforce. These uncertainties around benefits and employment need to be clarified for people with MD.

Other barriers to employment cited by participants included suitable transport, inaccessible buildings, not having a PA (or insufficient PA hours) which concur with similar studies, though employer attitudes was cited by others (Muscular Dystrophy UK 2010). Some participants reported the unavailability of appropriate assistive technologies to support education, work and independence and this has been borne out in the literature (Stumbo et al. 2009). Participants questioned if the Public Sector was meeting the recommended quota of employing 3% staff with a disability as per the Disability Act 2005 (Department of Public Expenditure and Reform 2015).
5.7 Financial implications

Participants’ conditions impacted on them financially and this has been reported in the international literature (Muscular Dystrophy UK 2010; Landfeldt et al. 2014; Larkindale et al. 2014). In Ireland, MDI reported that 64% participants recounted that their condition had a ‘very big’ or ‘big’ impact on them financially (MDI 2014a). Similar results (67%) were reported in the UK and in addition, 40% of families struggle to pay their bills and 80% think that the benefits they receive are inadequate to cover their costs (Muscular Dystrophy UK 2010).

There are a myriad of reasons why people with MD are burdened financially and these include:

- Employing personnel to do physical chores and assist with daily care
- The cost of visits to health professionals
- The cost of medications and their administration (medical card) and other health-related expenses like diagnostic tests and assessments
- The cost of assistive equipment and repairs thereof
- The cost of essential housing adaptations when grants were unavailable (verified by Kierkegaard et al. 2009; Henschke 2012; MDI 2014a)
- Limited income as a consequence of reduced opportunities for education and employment (Economic and Social Research Institute 2015:5)
- Increased cost of living when confined to the home e.g. heating, electricity and prepared food
- Increased cost of adapted vehicles and transportation: more dependent on the car is one can drive, otherwise compelled to pay for taxis

Whatever social benefits/entitlements that are available are essential, but they are not equivalent to ‘out of work benefits’, though they go some way towards contributing to the extra financial cost of managing the condition (Muscular Dystrophy UK 2010). The consequence of the financial burden participants’ condition imposes on them is that participants do not socialise and remain at home; which is significant in a population who do not participate as much in social and lifestyle activities (Cup et al. 2011; Kierkegaard et al. 2011).

In summary, the financial burden MD imposes on people exists for many reasons. Having access to adequate finances is key so that people truly have the opportunity to live independently.
5.8 Voicing for change

Participants unanimously agreed that there was a need for essential information at the time of diagnosis and the nature of this information included: information about the condition, its management and the health professionals who would be involved in its management, informal and formal support services/networks and social services and related entitlements. All participants requested that a clear pathway be available from diagnosis onwards from one organisation at a unique contact number and suggested that all specialists, at the time of diagnosis, could issue their patients with a pamphlet containing relevant contact details. It is evident from the literature that self-determination and a good quality of life are related to people with disabilities engaging well with their centres for independent living (Bekemeier 2010).
6.1 Conclusions

6.1.1 Assistance and support
What was clear from participants in this study was that irrespective of who was involved, some form of assistance and support is essential to facilitate independent living. There was some confusion regarding the precise role of personnel who assist and support people with MD. Above all, many participants were unclear about the role of the PA, what the eligibility criteria are: to acquire PA, to obtain more PA hours when needed in the future, to secure funding and to engage with the application process.

6.1.2 Supporting and managing health
Health professionals’ knowledge levels regarding MD was considered by participants to be highly variable. The wait lists to access health professionals and diagnostic tests are prohibitively long such that people with MD end up self-funding appointments so as to avoid pain and discomfort and to continue to live independently. Multidisciplinary teams and GPs were praised for the important roles they play in supporting the health of people with MD.

Participants were not aware of the range of entitlements that were available to people with MD. In an effort to reduce the health-related costs for people with MD, participants suggested that diagnostic tests be free and that the medical card would be made available to all.

6.1.3 Assistive equipment
There are considerable delays with acquiring and repairing assistive equipment. In particular, many participants had experienced delays with repairing their wheelchairs and highlighted that being without a wheelchair had negatively impacted on their autonomy and independence. Participants had a preference for owning essential medical equipment and in the context of home security, would welcome free monitoring.

6.1.4 Physical environment
The application process for housing adaptations and payment arrangements vary geographically. In some cases adaptions to participants’ houses were not fit for purpose and did not take into account the individual needs of the person with MD. Outside of the home environment, many public buildings, facilities and amenities are unsuitable and inaccessible to people with a physical disability and do not comply with recommended

### 6.1.5 Education, employment and further training

Having adequate supports available while in the education system impacts on opportunities for further education and employment later. Participants were confused about which benefits and entitlements would have to be relinquished should they return to the workforce. Participants queried if the Public Sector was fulfilling the recommended 3% quota of employees with a disability. There were many challenges reported in the context of engaging with employment and these include: not having transport, not having a PA or insufficient PA hours, inaccessible buildings and the unavailability of assistive technologies in the workplace.

### 6.1.6 Financial implications

MD impacts financially on people with the condition and the cost associated with the condition includes: paying for assistance and support, medical- and health-related costs, assistive equipment, housing adaptations and reduced opportunities to engage fully with education, further training and employment.

### 6.1.7 Voicing for change

Participants agreed that there needs to be a clear pathway from diagnosis onwards and that the services that are currently available to people with MD are better resourced. There was also consensus that there should be one go-to organisation which would provide consistent information, source funding and PAs and process relevant applications on behalf of people with MD. Having one organisation would remove the inequity that exists when services and entitlements are compared nationally.
6.2 Recommendations

6.2.1 Assistance and support
In the context of assisting and supporting people with MD, there is a need to:

- Define and clarify the roles and duties of the personnel who assist and support people with MD
- Clarify the eligibility criteria and application process when applying for a PA
- Have one organisation to manage all aspects of the PA service

6.2.2 Supporting and managing health

- Health professionals need to inform themselves about MD so that they can provide MD-related information at the time of diagnosis
- Health professionals need to be educated about the role of the PA (who may need to be present when the person with MD engages with health professionals), their services in both the community and hospital settings
- The time to access health professionals, diagnostic tests and health-related entitlements needs to be reduced
- The range of health-related entitlements available to people with MD needs to be better publicised
- The Long-Term Illness Scheme should cover the cost of medical equipment and all MD-related medications
- The medical card should be available to all people with MD irrespective of means

6.2.3 Assistive equipment
Participants recommended that:

- The acquisition and repair of assistive equipment be expedited
- They could have the option of purchasing essential medical equipment (rather than renting it on a long-term basis) but that service agreements be included
- People with MD should have access to free home security monitoring

6.2.4 Physical environment
Participants recommended that:

- The application process and acquisition of funds for adapting houses needs to streamlined nationally
- Stage-wise payments are available to assist with financial budgeting
- Grants be flexible to meet the needs of people with MD if/as their condition changes
- Adaptations to a person’s house are tailored to the person with MD’s needs
• Public buildings and areas comply with disability-friendly and wheelchair-friendly standards in line with legislation

6.2.5 Education, employment and further training
Participants recommended that:
• Supports are available from childhood onwards when engaging with the education system
• There is clarity around which benefits and entitlements are surrendered when one steps back into education or the work force
• The Public Sector organisations are encouraged to meet the target of employing 3% of their workforce with a disability
• Employers consider the challenges faced by people with disabilities engaging with employment and that they take steps to reduce these, for example, making the building more accessible and providing suitable assistive technologies.

6.2.6 Financial implications
Participants recommended that:
• Energy companies consider reviewing their tariffs for people with a physical disability
• Government assesses the true cost and financial impact of having a disability and make realistic provisions thereafter

6.2.7 Voicing for change
Participants recommended that:
• There is a clear pathway for people with MD from diagnosis onwards
• Current services are better resourced
• There is a one organisation (one stop shop) which would provide consistent information, source funding and PAs and process relevant applications on behalf of people with MD.

6.3 Limitations
The sample for this study was limited to adult persons with MD encompassing all genetically determined muscle wasting conditions. The sample was recruited by MDI who acted as the gatekeeper. All participants were self-selected in that they chose to take part in the study and therefore findings reflect their views only.


Appendix 1: Systematic literature search - search terms

**Concept 1: Muscular Dystrophy**


**CINAHL**: (MH "Muscular Dystrophy") OR (MH "Myasthenia Gravis") OR (MH "Friedreich's Ataxia")

**Free Text**: “Muscular Dystrophies” OR Myodystrophica OR Myodystrophicas OR Myodystrophy OR Myodystrophies OR “Muscular Dystrophy” OR “Dystrophies, Muscular” OR “Dystrophy, Muscular” OR “Muscular Dystrophies, Limb Girdle” OR “Myopathic Limb-Girdle Syndrome” OR “Muscular Dystrophy, Limb-Girdle” OR “Muscular Dystrophy, Limb Girdle” OR “Limb-Girdle Syndrome” OR “Limb-Girdle Muscular Dystrophies” OR “Limb Girdle Muscular Dystrophy” OR “Limb Girdle Muscular Dystrophy” OR “Muscular Dystrophies, Limb-Girdle” OR “Distal Myopathies” OR “Myopathies, Distal” OR “Myopathy, Distal” OR “Distal Myopathy” OR “Muscular Dystrophy, Distal” OR “Distal Muscular Dystrophies” OR “Distal Muscular Dystrophy” OR “Muscular Dystrophies, Distal” OR “Tibial Muscular Dystrophy” OR “Muscular Dystrophies, Tibial” OR “Muscular Dystrophy, Tibial” OR “Udd Myopathy” OR “Myopathy, Udd” OR “Udd-Markesbery Muscular Dystrophy” OR “Muscular Dystrophy, Udd-Markesbery” OR “Udd Markesbery Muscular Dystrophy” OR “Finnish-Markesbery Muscular Dystrophy” OR “Finnish Markesbery Muscular Dystrophy” OR “Muscular Dystrophy, Finnish-Markesbery” OR “Udd Distal Myopathy” OR “Distal Myopathy, Udd” OR “Myopathy, Udd Distal” OR “Welander Distal Myopathy” OR “Distal Myopathy, Welander” OR “Myopathy, Late Distal Hereditary” OR “Myopathy, Distal, Early-Onset, Autosomal Dominant” OR “Myopathy, Distal 1” OR “Distal 1 Myopathies” OR “Distal 1 Myopathy” OR “Myopathies, Distal 1” OR “Muscular Dystrophy, Distal, Late-Onset, Autosomal Dominant” OR “Distal Myopathy 1” OR “Distal Myopathy 1s” OR “Myopathy 1, Distal” OR “Myopathy 1s, Distal” OR “Laing Distal Myopathy” OR “Distal Myopathy, Laing” OR “Myopathy, Laing Distal” OR “Laing Early-Onset Distal Myopathy” OR “Laing Early Onset Distal Myopathy” OR “Myopathy, Distal, Swedish” OR “Tibial Muscular Dystrophy, Tardive” OR “Distal Myopathy Markesbery-Giggs Type” OR “Distal Myopathy Markesbery Griggs Type” OR “Tardive Tibial Muscular Dystrophy” OR “Cardiomyopathy, Dilated, X-Linked” OR “Childhood Muscular Dystrophy, Pseudohypertrophic” OR “Childhood Pseudohypertrophic Muscular Dystrophy” OR “Duchenne Muscular Dystrophy” OR “Duchenne-Type Progressive Muscular Dystrophy” OR “Duchenne Type Progressive Muscular Dystrophy” OR “Muscular Dystrophy, Childhood, Pseudohypertrophic” OR “Muscular Dystrophy, Duchenne Type” OR “Muscular Dystrophy, Pseudohypertrophic” OR “Pseudohypertrophic Muscular Dystrophy” OR “Muscular Dystrophy, Pseudohypertrophic Progressive, Duchenne Type”
Dystrophy” OR “Landouzy-Dejerine Dystrophy” OR “Dystrophies, Landouzy-Dejerine” OR “Dystrophy, Landouzy-Dejerine” OR “Landouzy Dejerine Dystrophy” OR “Landouzy-Dejerine Dystrophies” OR “Muscular Dystrophy, Landouzy Dejerine” OR “Progressive Muscular Dystrophy, Facioscapulohumeral Type” OR “Facio-Scapulo-Humeral Dystrophy” OR “Facioscapuloperoneal Muscular Dystrophy” OR “Dystrophies, Oculopharyngeal Muscular” OR “Dystrophy, Oculopharyngeal Muscular” OR “Muscular Dystrophies, Oculopharyngeal” OR “Oculopharyngeal Muscular Dystrophies” OR “Oculopharyngeal Dystrophy” OR “Progressive Muscular Dystrophy, Oculopharyngeal Type” OR “Oculopharyngeal Muscular Dystrophy” OR “Muscular Dystrophy, Oculopharyngeal” OR “Dystrophies, Myotonic” OR “Dystrophy, Myotonic” OR “Myotonic Dystrophies” OR “Dystrophia Myotonica 1” OR “Myotonia Atrophica” OR “Atrophica, Myotonia” OR “Atrophicas, Myotonia” OR “Myotonia Atrophicas” OR “Steinert’s Disease” OR “Disease, Steinert’s” OR “Steinert’s Disease” OR “Myotonic Dystrophy 1” OR “Steinert Disease” OR “Disease, Steinert” OR “Steinert Myotonic Dystrophy” OR “Dystrophy, Steinert Myotonic” OR “Myotonic Dystrophy, Steinert” OR “Dystrophia Myotonica” OR “Dystrophia Myotonica” OR “Dystrophy, Myotonia” OR “Myotonia, Dystrophy” OR “Myotonic, Dystrophy” OR “Myotonia Dystrophica” OR “Dystrophica, Myotonia” OR “Dystrophicas, Myotonia” OR “Myotonia Dystrophicas” OR “Muscular Dystrophy, Congenital” OR “Congenital Myotonic Dystrophy” OR “Dystrophies, Congenital Myotonic” OR “Dystrophy, Congenital Myotonic” OR “Myotonic Dystrophies, Congenital” OR “Myotonic Dystrophy 2” OR “Ricker Syndrome” OR “Syndrome, Ricker” OR “PROMM (Proximal Myotonic Myopathy)” OR “PROMMs (Proximal Myotonic Myopathy)” OR “Dystrophia Myotonica 2” OR “Dystrophy Myotonica 2s” OR “Myotonic Myopathy, Proximal” OR “Myopathies, Proximal Myotonic” OR “Myopathy, Proximal Myotonic” OR “Myotonic Myopathies, Proximal” OR “Proximal Myotonic Myopathies” OR “Myotonic Dystrophy” OR “Syndrome, Walker-Warburg” OR “Walker Warburg Syndrome” OR “Muscle-Eye-Brain Disease, POMT1-Related” OR “Disease, POMT1-Related Muscle-Eye-Brain” OR “Diseases, POMT1-Related Muscle-Eye-Brain” OR “Muscle Eye Brain Disease, POMT1 Related” OR “Muscle-Eye-Brain Diseases, POMT1-Related” OR “POMT1-Related Muscle-Eye-Brain Disease” OR “POMT1-Related Muscle-Eye-Brain Diseases” OR “Muscular Dystrophy-Dystroglycanopathy (Congenital with Brain and Eye Anomalies), Type A, 1” OR “Pagon Syndrome” OR “Pagon Syndromes” OR “Syndrome, Pagon” OR “Syndromes, Pagon” OR “Warburg Syndrome” OR “Syndrome, Warburg” OR “Hydrocephalus, Agria, & Retinal Dysplasia” OR “MDDGA1” OR “Chemke Syndrome” OR “Syndrome, Chemke” OR “COD-MD Syndrome” OR “COD MD Syndrome” OR “COD-MD Syndromes” OR “Syndrome, COD-MD” OR “Syndromes, COD-MD” OR “Conegenital Muscular Dystrophy-Dystroglycanopathy with Brain and Eye Anomalies, Type A1” OR “Conegenital Muscular Dystrophy Dystroglycanopathy with Brain and Eye Anomalies, Type A1” OR “HARD Syndrome” OR “HARD Syndromes” OR “Syndrome, HARD” OR “Syndromes, HARD” OR “Cerebrooculare Dysplasia-Muscular Dystrophy Syndrome” OR “Cerebrooculare Dysplasia Muscular Dystrophy Syndrome” OR “Muscular Dystrophy, Limb-Girdle, Type 2K” OR

**Concept 2: Independent Living**


**CINAHL:** (MH "Assistive Technology Devices+") OR (MH "Activities of Daily Living+") OR (MH "Community Living") OR (MH "Assisted Living") OR (MH "Caregivers")
Free Text: “Personal assistant” OR “personal assistants” OR “care team” OR “care teams” OR “care person” OR “care persons” OR carer OR “family carer” OR “family carers” OR “healthcare worker” OR “healthcare assistant” OR “health care assistants” OR “healthcare workers” OR “health care worker” OR “health care assistant” OR “health care assistants” OR “health care workers” OR Nurse OR nurses OR nursing OR “special needs assistant” OR “special needs assistants” OR caregiver OR caregivers OR “Care Givers” OR “Care Giver” OR “Spouse Caregivers” OR “Caregiver, Spouse” OR “Caregivers, Spouse” OR “Spouse Caregiver” OR “Family Caregivers” OR “Caregiver, Family” OR “Caregivers, Family” OR “Family Caregiver” OR homecare OR “home carer” OR “home carers” OR homecarers OR “Assisted Living Facility” OR “Facilities, Assisted Living” OR “Facility, Assisted Living” OR “assisted living facilities” OR “Facilities, Residential” OR “residential facilities” OR “Facility, Residential” OR “Residential Facility” OR ‘assisted living technology’ OR ‘assisted living technologies’ OR “Housing” OR “Home” OR “homes” OR “house” OR “Lodging” OR “Family-Patient Lodging” OR “Family Patient Lodging” OR “Family-Patient Lodgings” OR “Lodging, Family-Patient” OR “Lodgings, Family-Patient” OR “Patient-Family Lodging” OR “Lodging, Patient-Family” OR “Lodgings, Patient-Family” OR “Patient Family Lodging” OR “Patient-Family Lodgings” OR “Patient-Family Lodgings” OR “Patient Family Lodging” OR “Patient-Family Lodgings” OR residence OR residences OR “Living, Independent” OR “independent Living” OR “independent life” OR “independent lives” OR “living independently” OR “Medical Devices” OR “Medical Device” OR “Device, Medical” OR “Devices, Medical Devices” OR Device OR Equipment OR “Self-help aides” OR “self help aides” OR “self-help aid” OR “self help aid” OR “self-help devices” OR “Device, Self-Help” OR “Devices, Self-Help” OR “Self Help Devices” OR “Self-Help Device” OR “Assistive Technology” OR “Assistive Technologies” OR “Technologies, Assistive” OR “Technology, Assistive” OR “Assistive Devices” OR “Assistive Device” OR “Device, Assistive” OR “Devices, Assistive” OR “Assistive tools” OR “Assistive tool” OR “Wheel Chairs” OR “Chair, Wheel” OR “Chairs, Wheel” OR “Wheel Chair” OR Wheelchair OR wheelchairs OR “assisted bicycle” OR “assisted bicycle” OR Adaptations OR aids OR “Unattended polysomnography” OR bipap OR cough OR catheter OR catheters OR “Speech Synthesizers” OR “Speech Synthesizer” OR “Synthesizer, Speech” OR “Synthesizers, Speech” OR “Text Telecommunication” OR “Telecommunication, Text” OR “Telecommunications, Text” OR “Text Telecommunications” OR “Augmentative and Alternative Communications Systems”
Appendices

Appendix 2: Systematic literature search - the process

Defining the key concepts
The key concepts for the search were muscular dystrophy (MD) and independent living. The team agreed that an exhaustive list of MD should be applied where possible. The group defined independent living as any intervention which allowed greater independence for the person with muscular dystrophy. This led to a broader interpretation of subject terms including carers, assistive equipment and specialist equipment as well as looking for words relating to the term independent living and quality of daily life activities. A list of the terms searched is available in Appendix 1.

Development of search terms
Once the initial concepts were defined by the research team, the Librarian used a number of techniques to capture the relevant search terms relating to each concept. Initial scoping searches were run in both PubMed and CINAHL. These searches provided a list of synonyms provided by MeSH terms and CINAHL headings. The scoping search results were also manually scanned to look for additional author keywords as provided in the article bibliographic records.

Once a set of search terms was developed, a meeting was held with the research team to finalise the search string. The Librarian proceeded to run a series of systematic searches using the same terminology and the same search criteria. Six databases were selected for searching: PubMed, CINAHL, PsycINFO, ProQuest Nursing & Allied Health, British Nursing Index and Medline. This database spectrum ensured wide coverage of the literature in this subject area. Filters of English Language and peer reviewed were applied, where available within the database. All articles were run from 2005 onwards. The searches were all run on the 13th May 2015 and article number results are accurate as of this date.

Running the searches

EndNote
A central Endnote Library was set up to manage the results of the database searches. Once searched the results of each database was directly imported into Endnote. Smart Groups were created to manage the search results. A smart group, in Endnote, is created by a user with certain searching criteria to dynamically update groups as existing references are edited and new references are added to the library. It is similar to a canned search. Smart groups were used to track the origins or articles from the different
databases. Smart groups were also used to quickly differentiate between original and duplicate articles once the Library was populated.

Managing the search results

Deduplication of results

A combination of automated and manual searches were run to remove duplicates from the Endnote Library. Of the total number 1713 collated across the six databases 720 duplicates were identified. This left a remainder of 993 articles for further review.

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<thead>
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<th>Independent Living</th>
<th>Combined</th>
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</table>
Appendix 3: Systematic literature search - flowchart of the results

Documents/ URLs recovered from the search (n=1,713)

- Documents/URLs excluded as duplicates (n=720)
- Documents/URLs excluded as related to ‘paediatrics’ (n=286)
- Documents/URLs excluded - deemed not related to the review question after reading title (n=654)

Documents/URLs for consideration (n=55)

- Documents excluded – not relevant to the review question after reading the abstract (n=34)

Final number of articles included in the literature review (n=21)¹

¹ Other relevant grey literature and government reports were also included in the final literature review.
Appendices

Appendix 4: Letter of invite to Muscular Dystrophy Ireland members

April 2015

Dear MDI member,

My name is Dr Honor Nicholl and I am an Assistant Professor in the School of Nursing and Midwifery in Trinity College, Dublin. Along with some of my colleagues, I am currently undertaking a research study entitled “Exploring the challenges experienced by people with muscular dystrophy living independently” which is being funded by the Irish Research Council. The purpose of the study is to further investigate particular issues reported in MDI’s National Survey published in 2014 in which a questionnaire was distributed to all MDI members (670) and 171 people responded. Some of the possible contributory factors affecting independent living require further investigation.

I am contacting you as a person with muscular dystrophy as your experiences of what is required for independent living are relevant to this research study. This is the first notification to invite you to contribute to a focus group interview which will be held in one of four locations (most likely Dublin, Tullamore, Cork, Galway; to be confirmed) in early June 2015.

If you need any further information, please contact Clair Kelly (Information and Research Officer, Muscular Dystrophy Ireland) on 01 623 6414 or by e-mail: clair@mdi.ie.

I would be really grateful for your co-operation and look forward to further contact with you in relation to this study.

Yours sincerely,

_____________________

Dr Honor Nicholl

School of Nursing and Midwifery, Trinity College Dublin, Dublin 2.
Appendix 5: Participant Information Leaflet

Title of study: Exploring the challenges experienced by people with muscular dystrophy living independently (MD IndoLiving).

Further information about the study: The purpose of this study is to further investigate particular issues reported in MDI’s National Survey published in 2014 – in particular, to further explore the factors which hinder people with muscular dystrophy from living independently. The objectives of the study are to explore:
To what extent does not having a personal assistant impact on persons with muscular dystrophy living independently?
Why are there delays in accessing necessary assistive equipment?
What are the factors hindering access to medical care?
Why is medical card uptake so low?
What are the specific barriers preventing people with muscular dystrophy from accessing suitable housing or the financial help to facilitate adaptations to existing housing?
What are the main barriers encountered by people with muscular dystrophy in seeking employment, further training or education?

Procedures: You have been invited to participate because as a person with muscular dystrophy, your experiences of what is required for independent living are relevant to this research study. Other persons with muscular dystrophy have also been invited.

If you decide to participate in this study you are invited to attend a focus group interview with other people with muscular dystrophy. Each focus group will take approximately 60-90 minutes and will be audio recorded. You may have access to a copy of the summary of the outcome of the focus group, if you wish. There are four focus groups and these will take place in Dublin (2nd and 11th June), Galway (4th June) and Cork (10th June); venues to be confirmed. A payment of up to €40 will be given to assist you in travel expenses and light refreshments will be available at the venue.
Before you can be involved you will need to:
- let Dr Aileen Lynch know that you are attending by contacting her at amlynch@tcd.ie or 01 896 8571
- sign the consent form before the focus group commences (in the presence of the investigator/researcher)

**Benefits:** There may be no direct benefit for participants but the information collected will help provide further data on the identification of specific factors which hinder independent living for people with muscular dystrophy. Once identified, the barriers to independent living can be tackled so the findings have the potential to impact positively on people with muscular dystrophy. The potential benefits are that people with muscular dystrophy, support groups and policy makers will be better informed so that appropriate changes can be made to better support those with muscular dystrophy who wish to live independently. Increasing independence will have other potential long-term benefits such as positively impacting on work, education/training, social engagement and travelling outside the home.

**Risks:** It is not anticipated that there will be any adverse outcome for you. If any participant becomes upset in any focus group they will be provided with support at the time and provided with information about appropriate support services.

**Exclusion from participation:** You cannot participate in this study if any of the following are true: You do not have muscular dystrophy or, having been invited, have not agreed to participate in the study.

**Confidentiality:** Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the focus group. All information cited in the report or any future publications arising from this study will not identify you. All information/data will be held in a secure locked cabinet accessible only by the researchers and all computerised data will be stored on a password protected computer only accessible by the research team.

**Compensation:** This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

**Voluntary Participation:** If you decide to volunteer to participate in this study, you may withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.
Stopping the study: You understand that the investigators may withdraw your participation in the study at any time without your consent.

Permission: This research study has received ethical approval from the School of Nursing & Midwifery, Trinity College Dublin.

Funding: This study has been kindly funded by the Irish Research Council.

Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Dr Aileen Lynch who can be contacted by email: amlynch@tcd.ie or telephone: 01 896 8571. If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once. You agree that anonymised data from the study may be stored and used in future related studies without further consent being sought from you.

I really appreciate you taking the time to read this information leaflet.

Yours sincerely,

____________________
Dr Honor Nicholl
School of Nursing and Midwifery, Trinity College Dublin, Dublin 2.
Appendix 6: Participant Consent Form

TITLE OF STUDY   Exploring the challenges experienced by people with muscular dystrophy living independently (MD IndoLiving)

PRINCIPAL INVESTIGATOR Dr Honor Nicholl (telephone: 01 896 3702; email: nichollh@tcd.ie)

BACKGROUND
The purpose of this proposed study is to further investigate particular issues reported in Muscular Dystrophy Ireland’s (MDI’s) National Survey published in 2014 in which a questionnaire was distributed to all MDI members (670) and 171 people responded. Some of the possible contributory factors affecting independent living require further investigation.

This study has been granted ethical approval from the School of Nursing & Midwifery, Trinity College Dublin and has been kindly funded by The Irish Research Council.

The aim of this study is to investigate issues that may impede individuals with muscular dystrophy from independent living.

The key objectives of the study are to explore the issues which impede individuals with MD from independent living in terms of:

- assistance and support
- supporting and managing health
- the physical environment
- education, employment and further training and
- financial implications.

PARTICIPATION WILL INVOLVE
You have agreed to take part in an audio recorded focus group on one of the following dates: Dublin (2nd and 11th June), Galway (4th June) and Cork (10th June). This will take approximately 60-90 minutes to complete. Each participant will be given a payment of up to €40 to assist in travel expenses. You will be offered a copy of the summary of the outcome of the focus group, if you wish. All information collected in this study will be treated confidentially. Your identity will remain confidential at all
times and will not appear in any related publications. This consent form needs to be signed in advance of the focus group interview and in the presence of the investigator or member of the research team.

DECLARATION
I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I agree that anonymised data from the study may be stored and used in future related studies without further consent being sought from me. Data from the study will not be used in future unrelated studies without further specific permission being obtained. I understand that I may withdraw from the study at any time.

<table>
<thead>
<tr>
<th>PARTICIPANT'S NAME</th>
<th>CONTACT DETAILS</th>
</tr>
</thead>
</table>

<table>
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<tr>
<th>PARTICIPANT'S SIGNATURE</th>
<th>Date</th>
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</thead>
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Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and have fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

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<tr>
<th>INVESTIGATORS'S SIGNATURE</th>
<th>Date</th>
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Appendix 7: Participants’ Biographical Data

Information about yourself
(or the MDI member you represent)

1. Are you?
   Male
   Female

2. What is your age?

3. What location BEST describes where you live?
   City
   Town
   Village
   Rural

4. What is your HIGHEST level of education?
   Primary school
   Secondary school
   Vocational training
   Undergraduate degree
   Postgraduate degree

5. Are you:
   Employed full-time
   Employed part-time
   Self-employed
   A homemaker
   A student
   Unemployed
   Other (please specify)

6. How would you describe your current living status?
   I live on my own
   I live with a partner or spouse
   I live with my parents
   I live with my child / children
   Other (please specify)

Thank you for your time, input to and support of this study.
Appendix 8: Interview Guide

Open question 1: What kind of supports do you think are essential to enable persons with muscular dystrophy to live independently?

Probe 1 Personnel
To what extent does not having a personal assistant impact on living independently?

Probe 2 Practical support: equipment
Why are there delays in accessing necessary assistive equipment?

Probe 3 Practical support: living environment
What are the specific barriers preventing people with muscular dystrophy from accessing suitable housing or the financial help to facilitate adaptations to existing housing?

Probe 4 Medical support
What are the factors hindering access to medical care; including physiotherapists, occupational therapists, other specialists?

Open question 2: How does your condition impact on you financially?

Probe 1 Personnel
Do you need to pay for additional personal assistance or medical care?

Probe 2 Practical issues
Have you had to spend money to adapt your house or physical environment?

Probe 3 Medical-related
Do you need to pay for medical care?
Have you encountered any problems accessing the long-term illness card or medical card or drug refund scheme?

Probe 4 Employment, further training, education
What are the main barriers encountered by people with muscular dystrophy in seeking employment, further training or education?
Are there any issues we have not covered that you would like to discuss or add?

Give participants a summary of the key outcomes from the interview and ask participants if the feedback is a true reflection.

Conclude with the 5 takeaway points.

Thank you.