


# Exploring the psychosocial impact of simple robotic assistive technology on adolescents with neuromuscular disease

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Laura Oldford<sup>1</sup> , Natasha Hanson<sup>2</sup>, Isabelle Ross<sup>1</sup>, Emma Croken<sup>1</sup> and Lise Bleau<sup>1</sup>

## Abstract

**Introduction:** Adolescents with neuromuscular disease face significant challenges accessing social leisure activities. Assistive technology has provided new opportunities for those with neuromuscular disease to augment their social lives and leisure pursuits. However, there is limited research evaluating the impact of these technologies.

**Methods:** This study employed mixed methods to evaluate the potential impact of simple robotics on psychosocial factors and quality of life for those adolescents living with neuromuscular diseases. Semi-structured qualitative interviews were performed, as well as the adult Psychosocial Impact of Assistive Technology Device (PIADS) with 9 adolescents, ranging in age from 13 to 19 years old.

**Results:** Thematic analysis of the qualitative data resulted in five major themes: everyday lives and seasonality; socialization; leisure activities; robotics as a leisure activity; and ease of use of robotics. The PIADS found the individual scores demonstrated a range from very little yet positive perceived impact to maximum positive impact in each subscale (competence, adaptability, and self-esteem).

**Conclusions:** Simple mainstream robotics, paired with personalized access methods to control them, offer potential leisure and social integration opportunities to adolescents with neuromuscular diseases in a variety of settings, indoors and outdoors. The findings of this study suggest there are opportunities for this type of mainstream technology to be applied not just to adolescents, but potentially children of all ages with neuromuscular disease, across a variety of environments.

## Keywords

Age-related rehabilitation, activities of daily living, assistive technology, disability, occupational therapy, rehabilitation devices, smart systems [rehabilitation], virtual reality, therapeutic recreation, quality of life

## Introduction

Neuromuscular diseases (NMDs) are a heterogeneous group of inherited, progressive diseases.<sup>1</sup> There are many different types of NMDs. Although precisely how many currently exist is difficult to determine, Van der Beek et al.<sup>2</sup> estimate that there are approximately 600 different types of NMDs (p. 1030). In fact, Muscular Dystrophy Canada supports people with over 150 different types of NMDs.<sup>3</sup> Neuromuscular diseases affect the function of the various components of the peripheral nervous system,<sup>4</sup> and are usually characterized by early-onset, considerable long-term morbidity and

<sup>1</sup>Stan Cassidy Centre for Rehabilitation, Horizon Health Network, Fredericton, Canada

<sup>2</sup>Qualitative Methodologist, Research Services, Horizon Health Network, Saint John, Canada;

### Corresponding author:

Oldford Laura, Recreation Therapy, Stan Cassidy Centre for Rehabilitation, 800 Priestman Street, Fredericton E3B 0C7, New Brunswick, Canada.

Email: [laura.oldford@horizonnb.ca](mailto:laura.oldford@horizonnb.ca)



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functional disability.<sup>1</sup> Muscle weakness is one of the predominant clinical manifestations of NMDs.<sup>5</sup> Neuromuscular diseases do vary in magnitude and intensity, but they carry some common characteristics including (i) muscle weakness, (ii) muscle loss, (iii) movement issues, and (iv) reduced pulmonary function.<sup>6</sup> The above characteristics are progressive and translate into deterioration over time in activities of daily living (ADL) that require finger and arm strength, and in personal mobility.<sup>7</sup>

Consequently, as they deteriorate, the above common characteristics may present significant challenges in other domains of life for individuals with NMD and impact their Quality of Life (QOL). Quality of Life has been defined as the, “physical, social, and emotional aspects of a person’s well-being that are relevant and important to the individual”.<sup>1</sup> It is sometimes assumed that reduced physical function and greater disease severity are the main factors determining an impaired QOL. Reduced physical function and greater disease severity certainly are factors, however in reality QOL is a multidimensional concept that is not based solely on the absence of disease or illness.<sup>1</sup> Many factors impact QOL, including but not limited to: personal, cognitive, social, relational, and environmental factors.<sup>1</sup> The QOL framework developed by Schalock and Verdugo,<sup>8</sup> which has been internationally validated, was informed by a systems perspective. They take into account conceptualization of bioecological domains, such as macro (society-related factors), meso (community agencies/organizations), and micro systems (the immediate social setting, such as family).<sup>8</sup> This framework consists of eight domains, representing three broad areas (i) independence, (ii) social participation, and (iii) well-being which combine to provide an indication of an individual’s QOL.<sup>8</sup>

As therapeutic options are sometimes limited for individuals with NMD, long-term preservation of QOL is often a main goal of medical care.<sup>9</sup> Unfortunately, this goal is not always easy to attain. Although as mentioned, QOL is a multidimensional concept, the reduced physical function and greater disease severity that can accompany NMDs are important to consider in this context. Evidently, the common characteristics of people presenting with NMD, as per above, may present barriers, acting to inhibit or diminish an individual’s QOL. Speaking to this, Garcia et al.<sup>10</sup> note as NMDs progress, this disease progression can negatively impact an individual’s health status, autonomy, and independence (p. 246). Garcia et al. (2015) also cite a reduction in functional capacity, and progressive loss of physical capacity as components linked to a diminished QOL for these individuals.<sup>10</sup> Due to physical disability, adolescents with neuromuscular diseases face significant challenges accessing activities they can engage in independently and have more limited in-person socialization opportunities compared to their able-bodied peers.

Not surprisingly, reduced social participation in ADLs and leisure has been linked to a decrease in QOL for individuals presenting with disability.<sup>2</sup> People with disabilities show higher levels of loneliness, a lack of friends, and fewer opportunities to be with the friends they may have compared to people without a disability.<sup>11</sup> This pattern often spirals from the general lack of opportunities to participate in leisure opportunities, and thus less opportunity to socialize, meet new people and establish, or maintain strong relationships with others.<sup>12</sup> Consequently, a lack of leisure opportunities may lead to the development of dependent behavioral patterns, learned helplessness and depression.<sup>13</sup>

The rapid advancement of technology, specifically assistive technology (AT) has opened up new opportunities to positively impact an individual’s capacity to perform activities and participate in society. According to Cook and Polgar, assistive technology is defined as “a broad range of devices, services, strategies and practices that are conceived and applied to ameliorate the problems faced by individuals who have disabilities” (p.5).<sup>14</sup> Consequently, AT offers an opportunity for adolescents with NMD to augment their leisure lifestyle by being able to access opportunities that their disability has previously blocked their participation in. However, there is limited research or best practice on this growing area.

There are many commercially available leisure and assistive technology tools that have the potential to be utilized by adolescents with NMD as well as their peers, but further clinical investigation and support are needed to identify the impact of such tools. Specifically, a new generation of robotics, available as mainstream technology to the general public, may offer several opportunities uniquely advantageous to children and adolescents with NMDs. These robots show great potential to both increase and enhance current leisure participation within this population. While an assistive robot aids the human user in some regard, there are interactive robots which are usually designed to entertain or be used socially by an individual.<sup>20</sup> Examples of these small and simple interactive robots, which are controlled remotely through such means as a tablet or smart phone, include: Sphero, Dash and Dot, and Ollie. This is exciting, as participating in leisure activities in general has been shown to (i) promote skill development; (ii) provide positive peer interaction; (iii) influence greater independence; and (iv) promote autonomy and self-determination.<sup>15,20</sup> The currently available interactive robotics show great promise in contributing positively to the social participation of adolescents with NMDs, and in turn, potentially could contribute to QOL.<sup>8</sup>

Simple robotics show great potential for many reasons, a few of which are that (i) they are available for purchase to the general public in local stores, and online; (ii) they offer various controller options in collaboration with assistive technology tools that can become accessible for all levels of physical abilities; and (iii) they are designed for both indoor

and outdoor use, making them suitable for back yards, community parks, schools, school yards, rural settings or urban spaces, on grass, gravel, snow, sand, or even water. These factors should combine to facilitate their use for children and adolescents with NMDs, as they should allow them to engage in leisure activity without concerns for transportation or building accessibility issues. Most importantly they could provide an opportunity to get outside, to participate positively in their community, to interact with others, and to form and maintain strong relationships with peers and family members.

Robots are currently available as mainstream technology, but there has been no evaluation or assessment that we have found from a clinical or research standpoint of their use for individuals with neuromuscular disease. Consequently, the goal of this study was to evaluate the potential impact of simple robotics on psychosocial factors and QOL, while the scope was narrowed to those adolescents living with NMDs.

## Methods

This study employed a concurrent embedded mixed methods design, wherein the quantitative data collection was embedded in the predominantly qualitative data,<sup>21</sup> in order to evaluate the potential impact of simple robotics on the quality of life for those people living with NMDs. Quantitative methods were used to describe the effects of an assistive device on functional independence, well-being, and quality of life. Qualitative methods consisted of conducting semi-structured interviews with participants in order to learn about their daily lives, the potential impact of simple robotics on their quality of life and their social interactions.

## Participants

Inclusion criteria were (1) anyone over the age of twelve, (2) with a diagnosed neuromuscular disease, and (3) who was a client at the Stan Cassidy Centre for Rehabilitation. Exclusion criteria were (1) those who the researchers decided, using their clinical expertise with this population and knowledge of clients from referring clinicians, were unable to comprehend and answer the qualitative interview questions, or (2) unable to learn how to use the Simple Robotic technology. The study contained both adults and adolescents ( $n = 17$ ), however, only the results for participants 19 years of age and under ( $n = 9$ ) are reported herein, as they represent an important and distinct subset of the population.

There were 9 adolescents who participated in the study, the results for them are reported below. These participants ranged in age from 13 to 19 years old and were mainly male (8/9 participants). They lived in predominantly urban areas (8/9 participants). All lived at home with their parents. All had mobility impairments, with 4/9 being non-ambulatory and relying on a power wheelchair for their indoor and

outdoor mobility. 5/9 were able to stand for short periods and ambulate short distances. 5/9 had significant upper extremity limitations affecting their fine motor skills and reach. All presented with various degree of decreased upper extremity strength and endurance.

## Procedure

The Canadian based study was approved by the Horizon Health Network Research Ethics Board (RS# 2018-2585; 10311). Informed written consent was obtained from all participants over the age of 19 in the study and in the case of those under 19 informed written consent was obtained from their legal guardians and participants assented to participate. All study data were collected by Horizon Health Network employees. Participants were recruited through the Stan Cassidy Centre for Rehabilitation (SCCR). The SCCR is a specialty, tertiary, Center equipped and staffed to treat the most complex neurological conditions. Potential participants were identified by SCCR clinicians, based on their leisure interests and clinical goals, who then referred them to the researchers (who are clinicians also within SCCR). The interested potential participants were informed verbally about the study in person at SCCR and given the informed consent forms for consideration. Written informed consent (as well as assent for children and youth) was then obtained in person at SCCR when the decision to participate was made.

A screening form was collected on all participants, after consent, by the researchers at SCCR. This included general demographic information, as well as their diagnosis, physical and cognitive function, social life, leisure activities, and, technology use. Diagnosis, physical and cognitive function were collected from the participant's medical files. Participants were then scheduled to have a combined demonstration and trial of simple robotic assistive technology at a time and place of their convenience. The robotics trials were conducted both in the home community of participants, with some in their homes, as well as at SCCR, depending on the reference of the participant. After the trial, the principal investigator completed the study measures with the participants.

## Measurements

The adult Psychosocial Impact of Assistive Technology Device (PIADS) was conducted after participants completed the robotics trials, as well a brief semi-structured interview. The PIADS is a 26-item, self-report questionnaire designed to assess the effects of an assistive device on quality of life, functional independence, well-being.<sup>16,17</sup> The PIADS has been used researched and found to have test-retest reliability, construct validity, and good internal consistency.<sup>16,17</sup>

The semi-structured interview with participants, which took approximately 20 min, asked about the participants'

daily life and the possible impact of the simple robotics on their quality of life and their social interactions. It investigated what participants felt about the trial experience and technology itself.

### **Intervention**

All participants had a robotics trial during which the principal investigator (a recreation therapist) provided the intervention. Each session (approximately 1 hour) began with setting up access to the auxiliary device (such as a tablet or smart phone), which functioned as the robot controller. This was selected based on the initial screening completed. Once set up, the client was able to trial the robots they chose, from the selection of Sphero, Dash and Dot, and Ollie, with any friends and/or family they chose to invite. These trials consisted of the participants controlling the robots and learning their functionality at either their own homes or at a rehabilitation facility. Sessions were conducted until an hour was reached or the participant stopped the trial. Informational handouts were provided to the participants at the end of each session on the robots they had trialed.

### **Data analysis**

The interview data consisted of audio recordings which were transcribed verbatim and the transcripts were then uploaded to Nvivo, a qualitative data analysis software. The data was subjected to inductive thematic analysis iteratively, as the interviews took place.<sup>19</sup> This allowed for the overarching themes to become clear over the course of the study and data saturation was reached. Our coding was team-based and the process consisted of 6 phases: (1) familiarization with the data; (2) initial coding; (3) organizing codes into themes; (4) review of themes; (5) naming and definition of themes; and (6) reporting.<sup>19</sup> Themes were agreed upon within the research team through consensus. Data saturation was reached. Also, in conjunction with the interview data the contextual information gathered through the Screening Form and the PIADS data were used to investigate possible thematic patterns and differences in relation to personal attributes such as age, gender, level of disability, and diagnosis. Descriptive statistics are reported for the PIADS data.

### **Results**

Thematic analysis conducted on the interview data by the research team resulted in five major themes, discussed below. In describing their daily lives three themes emerged: everyday lives and seasonality, socialization, and leisure activities. Themes in relation specifically to the trial were: robotics as a leisure activity and ease of use of robotics.

### **Everyday Lives and Seasonality**

In describing their daily activities, participants mentioned that they needed ongoing caregiver support and 4 participants also spoke about daily use of a wheelchair. When asked how much time they spent in bed daily the answers ranged from 6 to 12 h. Three participants said that they were in bed over 8 h per day.

The interviews were conducted over the summer months. Although they all went to school only 3 participants spoke about attending school. When asked how often they left their home all of participants were regularly outside of the home. The majority of participants (5/9) noted that the season and weather impacted how often they left the home. Winter in the province of Canada where all the participants resided is a cold and snowy season. As one participant, who needed caregiver support, described, “I like summer better because in the winter, with my chair, well I can’t really go everywhere, you know.” (Participant R6).

The season also impacted what leisure activities participants, for example one participant said, “Like when it’s summer I go out more, outside more than I do in the winter time. Because usually in the winter I’ll just stay inside but if it’s the summer I’ll probably go outside and do something sometimes.” (Participant R2).

### **Socialization**

All 9 participants discussed socializing with others, and 2 participants specifically discussed technology use for socialization at a distance (via online videogaming, social media, etc.). Four participants mentioned spending time alone for their leisure activities. It was most often family mentioned as those they socialized with on a daily basis, which would be expected, particularly given their living arrangements and age.

### **Leisure Opportunities**

While the majority of people discussed indoor (7/9 participants), sedentary (7/9 participants) leisure pursuits they took part in, 8 participants also mentioned social leisure activities and 5 participants discussed leisure activities that took place outside of the home. The majority of participants (5/9) mentioned video games in relation to leisure activities they liked to participate in. It is also notable that technology-based leisure activities were the predominant ones discussed by 6 participants.

One participant defined fun activities as, “Anything that helps me forget my problems for a while, stuff I like doing like video games, watching hockey, RC cars.” (Participant R12) They went on to say, “Well, computer is the easiest thing to do so I would watch YouTube and play computer games. It’s actually my favorite thing on the computer. And also, I watch TV.” (Participant R12)

One participant discussed that where they were able to participate in social leisure activities was limited by their being in a wheelchair, “I like playing games with my whole family and all my friends. Whenever they come over I am able to, I am not able to come to their house so it’s usually just when they are able to come to mine because it’s wheelchair accessible, my house, and theirs is usually not.” (Participant R2)

Only 3 participants discussed physically active leisure they took part in. Swimming was talked about by two participants, “I go to the [name of recreation centre] that’s my favourite spot to swim.” (Participant R17)

### Robotics as a Leisure Activity

Only 1 participant mentioned previous use of robotics, similarly interactive as those which were part of the trial, as a leisure activity. Therefore, the use of robotics was novel for the majority of the participants. Many participants wanted to test the robots because they were novel, “It sounded cool. I thought it would be interesting.” (Participant R8)

All participants found the use of the robotics an enjoyable activity. Several participants liked that the robotics were an interactive leisure activity, “Well it’s not like staring at a screen all the time, which I usually do. It’s more interactive.” (Participant R12)

Participants said they would use the robotics as a leisure activity to varying degrees, with the majority stating that they would play with it daily (5/9) with the other stating they would use it weekly or sometimes. In terms of where participants would use the robotics, if they owned them, most said both indoors and outdoors (5 participants), with 1 stating they would likely use them outdoors exclusively and 2 stating indoors exclusively. All participants stated they would use robotics for in-person socialization, if they owned one: I would play “[w]ith my friends and everyone you know, showing them how cool they are.” (Participant R13)

### Ease of use of robotics

Only a few of the participants (3) stated that the robotics they tested were easy to use, however, 6 participants found the robotics initially difficult to use but easier with time: “Well it was tricky at first but then after a while it got easier.” (Participant R1)

One participant felt frustrated in the use of the robotics, “[t]he Star Wars one, the BB9 and 8, I think, one was hard to control because it went faster.” (Participant R10)

Two participants discussed technical issues with the robotics: “I felt that some of the robots are like they fall over a lot and like whenever they fell over you couldn’t, it couldn’t get up itself, you had to reposition it.” (Participant R2). One participant noted that they would need the help of an able-bodied person to assist with using the robotics: “It

always had to be reset by another person if it fell over or something like but it was mostly fun.” (Participant R12)

### Psychosocial Findings

The PIADS results for participants are found in Table 1 and help describe the impact of using the simple robotics trialed. The subscales consist of competence, adaptability and self-esteem, all of which are sensitive to the impact of the technology being evaluated.<sup>16,17</sup> Competence refers to the feelings of efficacy and competence. Adaptability captures the inclination to take risks and try novel things. Self-Esteem is indicative of happiness, self-confidence, and emotional well-being. Scores can range from  $-3$  (maximum negative impact) through zero (no perceived impact) to  $+3$  (maximum positive impact). The dimension of Adaptability had the overall best score ( $m = 1.77$ ), followed by Competence ( $m = 1.33$ ), with Self-Esteem being the worst ( $m = 1.24$ ). Thus, overall the participants had modest positive impacts across the subscales. The individual scores for this project demonstrated a range from very little yet positive perceived impact to maximum positive impact in each subscale (competence, adaptability, and self-esteem). None of the participants identified any item has having a negative impact. Overall, the PIADS results indicate the simple robotics evaluated had positive impacts on participants, which reflects and further strengthens the positive qualitative findings.

### Discussion

The long-term preservation of quality of life is a main goal of medical care of the clinical management of individuals with NMD.<sup>9</sup> The evidence points to many barriers that exist in achieving this, including continual deterioration, reduced physical function, and disease severity.<sup>10</sup> Assistive technology interventions have been shown to be a valuable tool

**Table 1.** PIADS Results.

Participants	Competence	Adaptability	Self-Esteem
1	0.58	1.83	1.25
2	2.08	1.67	1.38
6	0.83	1.0	0.5
8	1.67	2.5	1.0
9	0.33	1.33	1.25
10	2.16	3.0	2.5
12	1.75	1.5	1.25
13	1.0	2.0	0.38
17	1.58	1.17	1.63
Lowest score	<b>0.58</b>	<b>1.0</b>	<b>0.38</b>
Highest score	<b>2.16</b>	<b>3.0</b>	<b>2.5</b>
Mean	<b>1.33</b>	<b>1.77</b>	<b>1.24</b>
Standard deviation	<b>0.62</b>	<b>0.61</b>	<b>0.59</b>

in optimizing quality of life of children and adolescents with disabilities.<sup>20,24</sup> The current study adds to this literature, with the findings showing the impact of simple robotic assistive technology on the QOL of adolescents with NMDs in three main areas: (1) social integration; (2) freedom of control and independence; and (3) as a leisure opportunity accessible outside of the home.

### Social Integration

Seven of the nine participants indicated through qualitative interviews that they would use the robotics for in person socialization if they owned one. Considering people with disabilities have fewer opportunities to participate in social leisure opportunities compared to people without a disability,<sup>11</sup> the impact of having accessible opportunities to try is very valuable with this population. Almost all participants in the research trial had a social companion with them and spoke of the potential the robotics for social integration. Although results from the adult participants are not the object of this paper, it is interesting to note how one adult participant summarized the social integration potential succinctly by looking back on their childhood, citing “[g]rowing up, it sucked being left out of things and I think that the big benefit with these robots are going to be for kids with illnesses similar to mine you know that are my nephews age and that way they have something that they can play with their friends and attract and be a part of the group again. Because normally when you’re in a wheelchair if you’re playing outside or you’re doing you know like tag or something like that you’re usually left out, you’re the one keeping score or something like that where with these you can just play with these and everyone is included.” (Participant R3)

Additionally, most of the participants reported indoor (7 participants) and sedentary leisure (7 participants) as a baseline. However, the robots showcased a leisure opportunity that was different. Several participants liked that the robotics were an interactive leisure activity, “Well it’s not like staring at a screen all the time, which I usually do. It’s more interactive.” (Participant R12)

Of the 26 items participants were asked to rate on the PIADS, the two highest items rated consistently amongst participants were the impact on their eagerness to try new things and their ability to participate. This is in line with the qualitative interview responses on ease of use and opportunity for control and independence. The PIADS has been found to be linked to the International Classification of Functioning, Disability and Health (ICF).<sup>22</sup> The 2 highest rated items from the current study are included in the Adaptability subscale of PIADS and represent a positive impact on the ICF Activities and Participation Domain.<sup>23</sup>

### Freedom of Control and Independence

Research has shown that despite a rising awareness of the importance of leisure activities as an integral part of maintaining QOL for people with disabilities; participation in leisure activities rates have not increased significantly.<sup>18</sup> The work of Badia, Orgaz, Verdugo, Ullan and Martinez<sup>12</sup> highlights that there are many factors to consider that contribute to the lack of participation in meaningful life activities, but there are a few primary reasons, including the fact that people with disabilities often have fewer *opportunities* to participate in leisure activities than people without disability (p. 2056). In addition to a depleted range of activities existing for people with disabilities, barriers also exist. These include but are not limited to, the inaccessibility to certain facilities, lengthy commutes to facilities, the individual’s need for care/assistance, as well as time and financial constraints for caregivers.<sup>18</sup>

Research participants indicated these barriers in the semi-structured interviews. One participant discussed that where they were able to participate in social leisure activities was limited by their being in a wheelchair, “I like playing games with my whole family and all my friends. Whenever they come over I am able to, I am not able to come to their house so it’s usually just when they are able to come to mine because it’s wheelchair accessible, my house, and theirs is usually not.” (Participant R2)

Consequently, any opportunity that has the potential for an individual with a neuromuscular disease to have the opportunity for control and independence is worth an investigation. With the low cost of the robotics (price range of \$30–250), the ability to use them anywhere (indoors, outdoors, school, therapy, etc), and the opportunity for independence with set up-robots have proven to be a valuable opportunity to try. The results of the study support this, both from the participant feedback as well as the principal investigators’ feedback. The PIADS results supported this as well, as the adaptability had the most positive impact and is most related to the concept of freedom of control. Not only did participants enjoy the actual trial and the robots, this result shows that positive participation in one avenue can transfer into being more open to trying other types of technology and leisure opportunities.

The primary investigators believe one of the main reasons this score was so high was the ability as clinicians to test them hands-on before trying them with the participant. As many adolescents with neuromuscular disease have a high level of physical disability, all technology is not necessarily suitable and easy to use. There was more time spent in preparing and analyzing the robots than in the actual face to face intervention with the participant, but it minimized frustrations and difficulties during the hands-on trial. For example, many of the participants actually, controlled the robotics through the joysticks of their power chair, which requires time to test which robots are compatible with that

technology. Consequently, despite high levels of physical disability, with time spent to screen and set up prior to the trials, the majority (6) of the participants stated that the robotics they tested were initially difficult but easier with time.

### *Leisure Activity Outside of the Home*

All participants found the use of the robotics an enjoyable activity (9 participants). In terms of where participants would use the robotics, if they owned them, most said both indoors and outdoors (5 participants), with 2 stating they would likely use them outdoors and 2 stating indoors. However, one key component that participants brought up was the seasonality of the weather in New Brunswick. It impacts their ability to access the outdoors for any reason. Consequently, while robotics could be a potentially valuable leisure opportunity outside of the home, its strength is also that they can be utilized in an indoor setting as an option when getting outdoors is not feasible. It may also be possible to integrate robots into the school extracurricular activities and academic curriculum to promote social integration and participation.

### *Limitations*

The small sample size of these reported research results is a limitation of the study. Further research is needed to verify these results in a larger NMD adolescent population, as well as with younger children and in a variety of settings.

### **Conclusions**

Due to their physical disability, adolescents with neuromuscular diseases face significant challenges accessing activities they can engage in independently, including leisure and socialization opportunities. Simple mainstream robotics paired with personalized access methods to control them, offer potential leisure and social integration opportunities to adolescents with neuromuscular diseases in various settings, including indoors and outdoors.

Feature matching of robots with participants prior to exposure to these robots not only lead to success during the trials but positively impacted the participants' feeling of competence and willingness to explore other activities. The ability of clinicians to be able to test and trial devices prior to the participant trials was considered paramount in reducing frustration and increasing confidence of the participant.

While the results show the potential for simple robotics to be trialed with children of all ages, more research is recommended to understand further how these devices potentially positively impact independent leisure and socialization in various settings, such as, home, school, and community settings with peers and family. Further research is also needed to build on these preliminary findings to provide robust evaluations of recreational technology as it

continues to develop for individuals with NMDs, to guide clinical best practice and optimize quality of life.

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### **Guarantor**

LO

### **Contributorship**

LO and LB researched literature and conceived the study. NH developed the qualitative methodology and was involved in protocol development, gaining ethical approval, and data analysis. IR and EC recruited participants, collected data and were involved in data analysis. LO, LB, and NH wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

### **ORCID iD**

Oldford Laura  <https://orcid.org/0000-0001-7702-5810>

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## Appendix A

### Semi-structured Interview Guide

1. Can you describe your typical day to me?

Probes:

- a. Who do you talk with on a daily basis?
- b. How much time do you spend in bed?
- c. How often do you go out of your home?
2. What do you like to do for fun?

Probes:

- a. Does this depend on the season (i.e., summer vs. winter)? If so, what are the differences?
- b. Who do you do these activities with?
3. How did you hear about simple robotics?
4. Why were you interested in testing simple robotic devices?

5. Thinking back to the day you tested the simple robotics, what did you think of using those devices?

Probes:

- a. What was it like to control the device?
- b. Did you have fun that day? If so, what was fun about it? If not, why not?
- c. What could have been improved about the testing of devices?
6. How often do you think you would use a device like those you tested, if you owned one?

Probes:

- a. Who would you use the device with?
- b. Where would you use it?
7. How does using the devices from the other day compare to the other things you do for fun?