

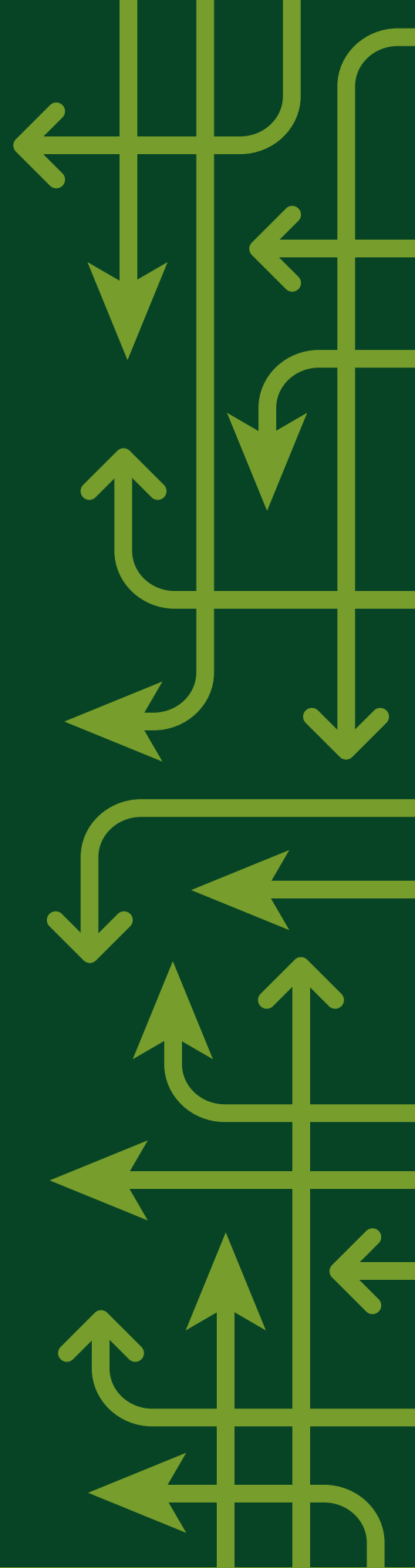


A PATHFINDERS REPORT

Entering Adulthood with Duchenne Muscular Dystrophy (DMD)

NOVEMBER 2023

This project and report were funded through an educational grant from PTC Therapeutics. PTC Therapeutics was not involved in the development of this project or the writing of this report.



Foreword:

*by Pathfinders Neuromuscular Alliance
Peer Researchers*

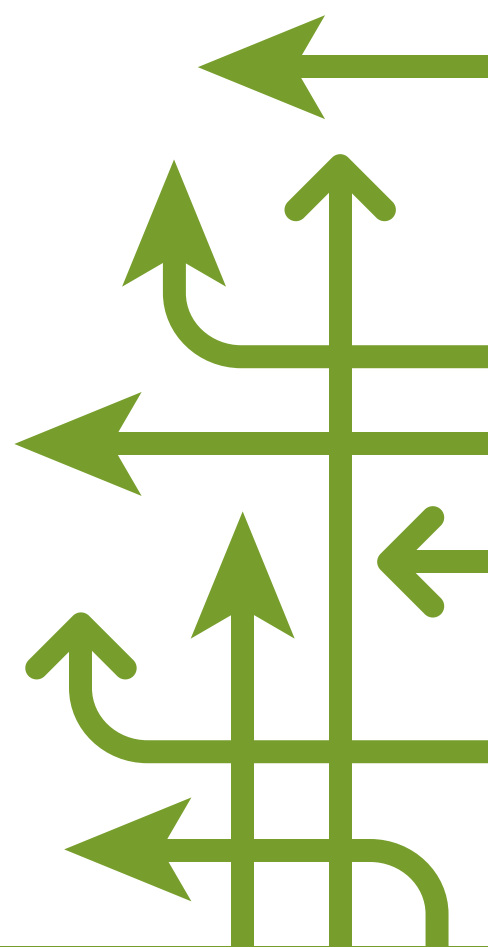
On behalf of the Pathfinders research team, we would like to present our report, *Entering Adulthood with DMD*. We are four adults with Duchenne Muscular Dystrophy (DMD). We share a passion for improving the understanding and knowledge of issues faced by people with DMD as they enter adulthood.

Our aim is for this report to be read by adults and young people approaching adulthood living with DMD. However, we also believe this report will be beneficial to those who provide care and support to young adults with DMD. This report may help these people understand how people with DMD think and feel as they move into adulthood. Most importantly, this report will highlight how that transition from paediatric care to adult care might impact individuals and our community as a whole.

We feel the insights given in this report brings a new dimension to existing DMD research. This is because our role as peer researchers has gave us the opportunity to offer our invaluable life experiences, and to steer the trajectory of this project. We directed the ideas which started this project, interviewed participants, and interpreted findings, leading to the development of this report.

We are saddened by the stories which our DMD community shared with us as part of this project. We are also frustrated by the difficulties and barriers which still exist for individuals with DMD, which have prevented us to fully participate in society. Hearing our peers talk about how they embarked on the journey of adulthood in whatever way suits them as individuals has been empowering and should act as an encouragement to us all. We hope is that these feelings will resonate with readers, helping them to better understand our experiences of becoming adults with DMD.

**Matthew Roberts, Jack Bosanquet,
Benjamin James and Ryan Dack.**



Executive Summary:

by Pathfinders' Jamie Hale (CEO)
and Dr Suzanne Glover



Pathfinders is a user led organisation run by and for people with muscle-weakening conditions, aiming to undertake research on issues important to the muscle-weakening community. This includes providing information and support to its members, as well as opportunities to challenge social inequalities.



About This Report

This report provides an accessible summary of the findings from the Entering Adulthood with Duchenne Muscular Dystrophy (DMD) project led by Pathfinders [1].

This project was led by Dr Suzanne Glover: a disabled researcher based within Pathfinders, along with a group of researchers living with DMD. Together the team designed and carried out the research which created this report. We know that this research approach brings a new and insightful perspective on the understudied area of entering adulthood. The research explores topics such as: education; confidence; change; independence, and social connection through in-depth interviews with people who have DMD.

We would like to express our gratitude to the small group of researchers (you can see more about our research team on page 08) who have worked tirelessly on this project since 2021. With heavy hearts, we remember two researchers in particular: Ryan Dack and Matt Roberts, who sadly passed away during the final stages of this report. Ryan and Matthew played a fundamental role in this project by conducting interviews, interpreting findings and developing the report. We hope that their work serves as a lasting legacy of their commitment and drive for change within the DMD community.

Whilst this report is aimed at people with DMD, it contains vital insights not just for the DMD community, but also families, teachers, health and social care professionals, and researchers. Our aim is for this work to highlight that the voices and needs of people with DMD must be at the core of their own transition to adulthood, as well as within wider policy and research development: just as they are at the core of Pathfinders' work.

1] This project and report were funded through an educational grant from PTC Therapeutics. PTC Therapeutics was not involved in the development of this project or the writing of this report.



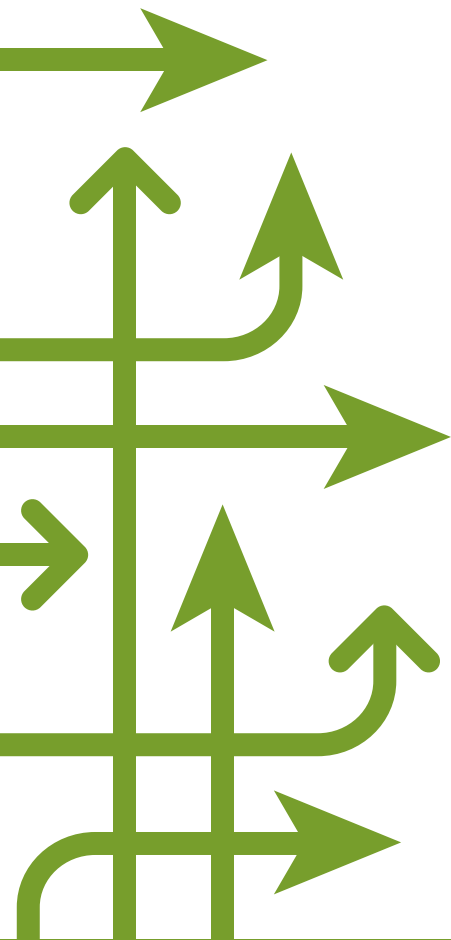
Research Findings, at a Glance

Entering adulthood with DMD is different for everyone. For some of the people with DMD we spoke to, becoming an adult involved establishing a new daily routine after finishing education, and/or beginning an alternative type of care and support (i.e., the use of paid personal assistants, also known as PAs). Despite these differences, those who provided feedback emphasised the common thoughts and feelings they experienced regarding themselves and the world around them as they entered adulthood. This included feelings about their own body, and how they felt about their inclusion in society as an adult.

Background

DMD is typically diagnosed in early childhood. People with DMD experience increasing muscle weakness as they grow older, affecting their ability to move their body and breathe without support. Adults with DMD often require assistance from others for personal and medical care. For example, many adults have PAs to assist with tasks such as eating and drinking, and personal care for attending their place of education, employment, or social events.

Developments in treatments such as steroid medications, ventilation and cardiac care have made positive steps in managing some aspects of living with DMD. This has enabled many young people to progress into adulthood living enriched and fulfilled lives, while navigating the everyday difficulties of life as well.



Background

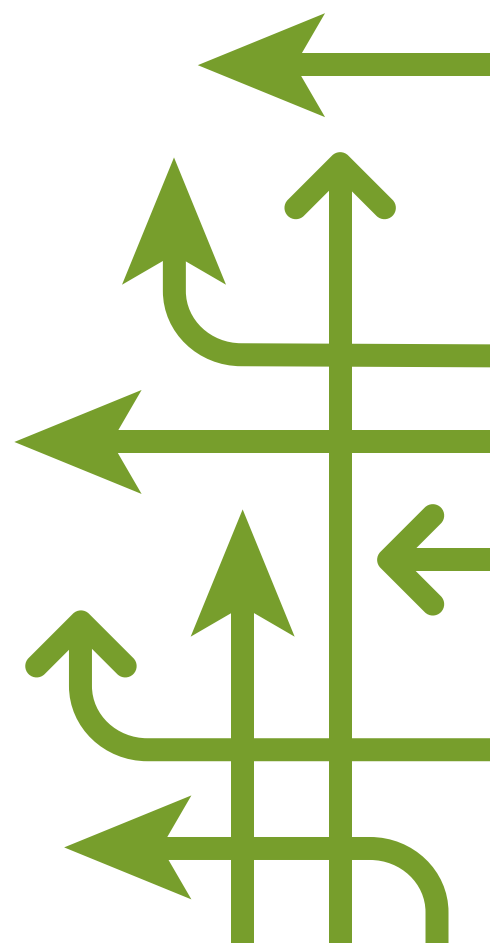
Our Pathfinders members and the wider DMD community celebrate many of the typical successes in our culture, for instance: educational qualifications; employment; marriage, and home ownership. These young people also use their interests, talents and expert knowledge for the wellbeing of themselves and others.

However, leaving childhood and becoming an adult can be a difficult experience for anyone with or without a disability. For people with DMD, this experience can be particularly challenging due to multiple changes occurring during this period. Some examples of these changes include:

- Physical differences in the body that can alter how someone can function
- Meeting different professionals, being introduced to new adult services, and leaving behind other professionals and children's services
- Leaving the familiar structure of education
- Entering into the working world
- Changes in perspective, both towards themselves and the world they live in

This research project questions how young adults with DMD think and feel about these changes. We also wanted to learn if the experiences of the transition from youth to adult care offered by health and social care services have changed in recent years.

To do this, we approached our questions with inclusive methods.

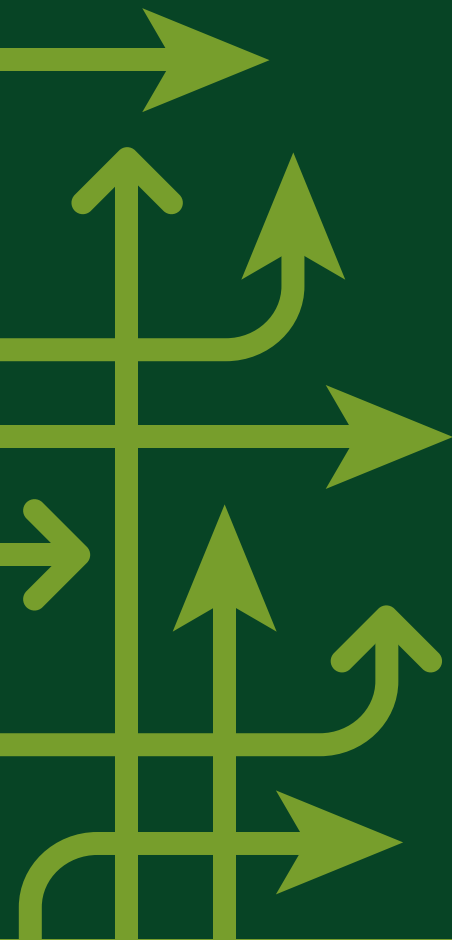


Pathfinders Research Team

People with DMD and other muscle-weakening conditions are at the forefront of this project, and are supported by university-based academics. The purpose of this research was developed by the ideas of adults with DMD, in a research approach often called co-production.

The Pathfinders Research Team has been established for close to 3 years, and continues to work in a virtual (online) research environment. Peer researchers are supported to lead and take ownership of research studies such as this one.

This project successfully received approval from the Health Research Authority (HRA) Ethics Committee in October 2021.



Meet the Pathfinders Team



From left to right:

Prof David Abbott, University of Bristol

Jack Bosanquet, Pathfinders

Ryan Dack, Pathfinders

Dr Suzanne Glover, Pathfinders

Dr Jon Hastie, Pathfinders

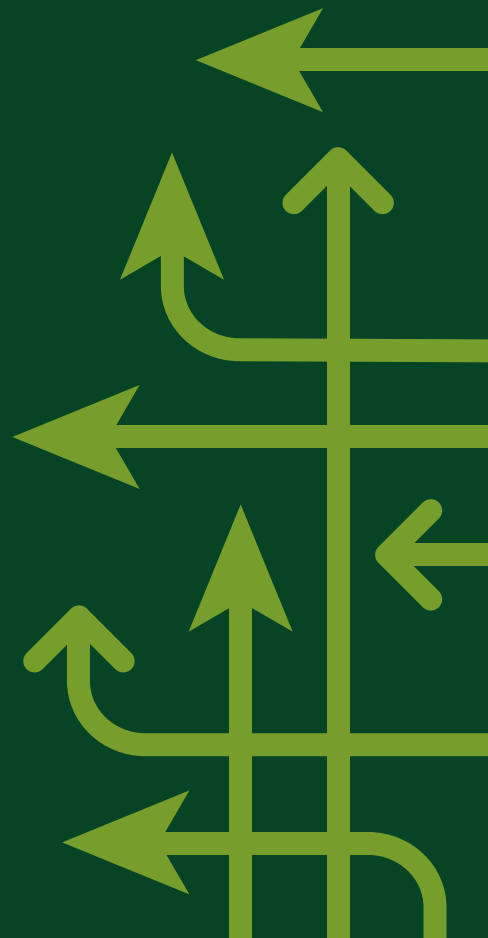
Dr Janet Hoskin, University of East London

Dr Helen Kerr, Queen's University Belfast

Dr Kirsty Liddiard, University of Sheffield

Dr George Peat, University of York

Matthew Roberts, Pathfinders



Overview of Research Findings

15 people with DMD took part in the study from the UK between November 2021 and January 2022. The participants were aged between 20-30 years old, with most between 25-30.

Going forward, we will talk about the 15 people with DMD who took part in the study as participants.

This report summarises the key areas talked about by people with DMD when describing their experiences of becoming adults. These include:

1. How do people experience life in education and beyond?
2. Why is confidence so important?
3. How do people cope with change?
4. What does independence actually mean for people with DMD?
5. How do people stay connected with others?

Following is a breakdown of our findings:



Key Areas of Research



1. How do people experience life in education and beyond?

Participants shared a wide range of memories regarding their time in primary and secondary education. Some said their time in education made them feel valued and supported, and they had the opportunity to make friends—although they often had trouble seeing and visiting their friends outside of school. Others felt isolated, that their ability to do well in education was not taken seriously, and were in some cases bullied.

Most participants went on to study within further education, such as college. Some motivations given for attending further education included:

- As a stepping stone towards university
- As an opportunity to be part of an environment where educational abilities were important
- As a way of continuing a social life, recommended by either the young person or their parents

Residential college was also a choice for some participants, as they felt this could help them fit in without a large focus on their disability. As participant George put it, such an opportunity meant they, “could just be one of the lads”. However, obtaining funding to make this possible was challenging, and described as a fight by George.

“I’d say that I enjoyed them [school years], I had a good group of friends at school.”

THEO

“...so I had to prove that my mainstream college couldn’t take me and couldn’t be able to do what I needed, but I did prove that, and that was one of the hardest things because a lot of them said, ‘Oh, you don’t need residential college, it’s not going to help you!’—but I had to really fight for it.” GEORGE

1. How do people experience life in education and beyond?

The move to university was seen as more complex than previous transitions experienced, such as progressing to college. This was largely due to having to receive funding and arrange the necessary care packages. However, having this support in place enabled them to attend university and sometimes live away from home.

“I’d say, yeah, I didn’t really do that much [at school]. I went to the cinema and went out a day here and there, but I’d say things really changed when I went to uni, that’s when I got a bit more sociable and started to do a bit more.” HARRY

For most participants, university attendance was a positive experience because it provided more opportunities to socialise with others. Also, those who attended university felt they received the support they needed to study. However, despite describing receiving support and guidance some still found university too stressful, and finished their courses early.



Of the young men who took part in the study went on to attend Further Education

6TH FORM



INDEPENDENT COLLEGE



RESIDENTIAL COLLEGE



UNIVERSITY



1. How do people experience life in education and beyond?

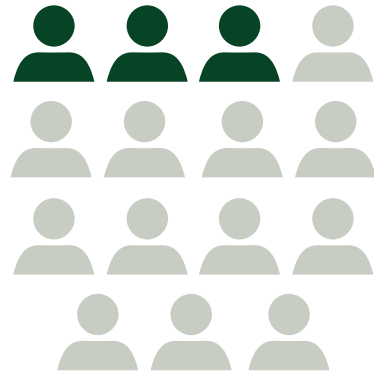
In terms of moving into the working world after education, many participants were motivated and keen to find work. Participants in this study worked in: journalism; healthcare communications; social media, and digital creation.

“For the past six months I’ve been working as the Social Media and Digital Creation Associate: so that involves creating social media posts, engaging with members of the charity.” SEBASTIAN

However, many participants faced barriers to find work. These included:

- Limited careers advice, meaning participants felt unsure about how best to apply their education to their work
- Experiences or fear of being treated unfairly by others because of living with DMD (i.e., discrimination)
- A belief that their degree did not match to actual jobs

“I’m an animator. Obviously that sort of work is to deadlines, so they [employers] think, “He’s disabled, he’s not going to meet that deadline.” GEORGE



PARTICIPANTS IN EMPLOYMENT

(in some capacity at the time of interview, despite 14 of the 15 participants having achieved a minimum of college education)



2. Why is confidence so important?

A key area that participants talked about was confidence. One question we asked participants was, "If you could change one thing about yourself, what would it be?" For most participants, the answer was, "Confidence".

Participants talked about confidence and how it might impact what they did and who they spoke to:

"I think it (being confident) would have opened a lot more doors and stuff. Everything would have been a bit more improved, I think. I just think it would open up a lot of things and it would get me a lot more involved in a few things." OLIVER

Having confidence was described by participants as important in talking and interacting with others. Some participants described feeling anxious and panicked in social settings. In turn, they felt this made them feel even more aware of how different they felt compared to others. However, we saw that many participants felt they had gradually increased their own confidence through their experiences entering adulthood.

"I think how much my confidence has grown, I think this compared to when I was younger, compared to five years ago, not even ten years ago, I'm a completely different person."

ADAM



3. How do people cope with change?

Participants described recognising changes in their body (such as fatigue and muscle weakness), and commented on how these symptoms impacted on their daily lives, feelings, and attitudes. These changes meant participants needed to take practical steps to adapt to their condition as they got older. For example, many participants discussed how they felt when they began using a wheelchair or breathing equipment.

Our research shows some of the different ways in which participants felt about challenges such as muscle weakness and fatigue, and how their feelings changed from day-to-day. For some people, beginning to use a wheelchair was really positive: despite feeling apprehensive at first, wheelchair usage meant they were no longer experiencing falls.

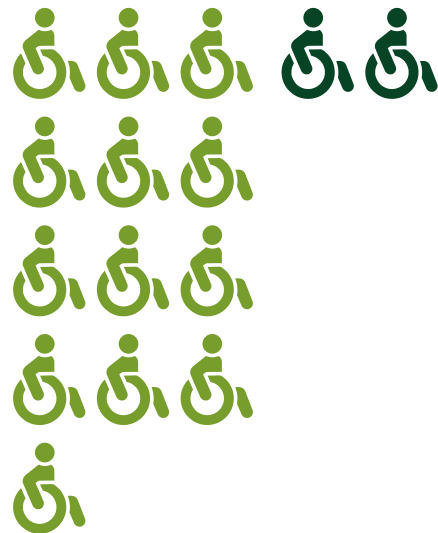
Many participants talked about, “getting on with life”, when having DMD. For Ibrahim and several others, this was important to emphasise, as many non-disabled people see disability as a tragedy.

“Some days are more difficult than others, but it’s just something that you get on with and carry on, just like with ordinary life, you know.” IBRAHAM

STARTED USING A WHEELCHAIR

AGED 11

AGED 20+



3. How do people cope with change?

“In my case, the fact that I’m so positive regardless, because from an able-bodied standpoint, people see a disability as a tragedy in some ways, but it’s not all about that. I still live a normal life day-to-day and enjoy things, you can enjoy life. It doesn’t mean you can’t. You know?” FRANCIS

Despite these positive and determined outlooks, participants also described experiencing “bad days”, in which they felt frustrated, worried, stressed or anxious about their condition.

“You know what you want to do, but you can’t do it.” GEORGE

“Sometimes you get stressed over trying to manage your health, making sure you’re keeping on top of infections and that sort of thing. I think that’s where the main stresses are and any sort of unplanned hospital admissions, anything like that really.” FINLEY

“I think frustration can be quite a big one [challenge], but it comes and goes really. Most days I’m pretty content, pretty happy with things, but, yes, you do get points of feeling frustrated or a bit low about it, yes.”
IBRAHIM

3. How do people cope with change?

To help manage these feelings, participants said that they would try to use humour, stay positive, and keep busy. Family members and friends were also described as important in helping them to not feel as stressed or worried. For example, one participant said that their mum did the “*stressing*” for them, which meant they could enjoy their life more.

“...it’s really important to stay positive. It keeps you busy, and I think if you keep your mind busy, yeah, I think that really helps with distraction. I don’t like worry and having too much anxiety—I think it helps that.” HARRY



4. What does independence actually mean for people with DMD?

Becoming an adult often means having more choice and control of your life. This is often known as *independence*. In this study, participants talked about what being 'independent' actually meant to them. Participants shared different ideas which reflected individual perceptions of independence. However, participants had ideas of independence which related to two types of thought: independence as *moving out*, and independence as *choice*.

“I always thought that me not moving out was a lack of independence but really it’s not, it’s just a different approach to things, I guess.” FRANCIS

For some participants, independence involved moving out of the family house and living in their own home. Others said being independent meant feeling in control, and being able to make decisions about things like their care. For this second group of participants, where they lived did not impact on how 'independent' they felt.

Participants told us that their choice and control could be supported by lots of factors, such as being included in the formal Education, Health and Care Plan (EHCP). Although many participants said they were involved in decision-making, they said this process was often vague. For example: Charlie said that his school wrote most of his EHCP, but they didn't "*understand the condition*", which made things "*difficult*".

“I think to me, I would say independence is probably about being able to have control over your life in terms of having your own choices.”

FINLAY

4. What does independence actually mean for people with DMD?

Our research showed how greatly participants valued their parents supporting and encouraging them to make their own decisions to become more independent. At the same time, other participants found it easier and less energy-consuming to ask their parents to speak on their behalf. This would occur during times when energy conservation is important, such as when they felt unwell, or were talking about their condition at hospital appointments.

“It’s like if I’ve got my mum with me, it’s like...and the doctor asks me a question, I’m like...I turn to her and sort of...because she’ll get the message across better than me.” SEBASTIAN

“It’s like, ‘Mum, can you ring them and tell them I’m not going to be in today?’ or something like that, because it just takes that off your back.”

JUDE

Participants told us that the relationships they had with professionals and their PAs were vital in ensuring they had choice and control over their own lives. It is important for these relationships to be built on empathy, understanding of DMD and for PAs especially, commonality and shared interest. Sebastian describes how having the choice of his regular carer makes him feel more comfortable.

“Because obviously when choosing care and choosing your carer, it’s about having someone who you get to know better, rather than someone who just comes in and you don’t really know them, you might feel quite uncomfortable.” SEBASTIAN

5. Staying Connected

Staying socially connected with others was a particularly important aspect of entering adulthood for participants in this research. Participants shared examples of how they connected with others through going to music concerts, eating out, and joining various social and sporting clubs. Participants said that staying socially connected was important for mental health and general wellbeing.

“Yeah, I think I’m, I suppose, quite active. I’ve got quite a few pals that I meet up with quite regularly, probably one or two times a week. I go to gigs quite often and stuff. So yeah, probably quite active, I like to go on holidays and out and about and stuff, so yeah.” HARRY

Some participants described the quality and size of their social circles. Francis explains, *“...as a disabled person, your [social] circle can be a bit smaller.”* Similarly, Theo commented how relationships were really important, but he doesn’t, *“...really have a massive group of friends.”* However, Theo does, *“...try to stay connected with a few friends”* regardless.

Some participants felt their relationships improved over time:

“I think for me, Sixth Form was probably better than the previous years at senior school because I suppose some people, not everyone, but some people, are maturing more. I felt like they accepted me more.” ALFIE

“I’ve got a good support group around me in terms of family and people in that way of friends with the condition. There’s always someone to talk to, so in that sense it’s okay.” FRANCIS

5. Staying Connected

We asked participants to think generally about what being disabled means to them as individuals within a society made up of disabled and non-disabled people. In particular, we asked how they thought their lives were similar, different, or just the same as non-disabled people. Although we saw many descriptions of life being 'normal' in comparison to non-disabled people, participants also described circumstances where they felt pushed to one side and left out by society because of their disability.

“Some people, I don’t think, always see you the same in society sometimes—they see you differently to everybody else.”

FREDDIE

One of the areas where participants told us they felt like an 'afterthought' was in relation to the accessibility of buildings and physical spaces. Poor physical accessibility meant that a great deal of planning was required when considering social events or meeting others. Opportunities for spontaneity were therefore limited.

Participants explained how day-to-day life and managing problems was something that notably created a sense of 'us' and 'them'.

“They [teenagers without DMD] can just, ‘Oh yeah, I’m going to my friend’s house’, yeah, just go that day, but I had to arrange in advance.” GEORGE

“You get to a restaurant, and you need a ramp to get in and they don’t have one—things like that.”
FRANCIS



5. Staying Connected

Interaction with others—particularly those who were non-disabled—was sometimes described as challenging and difficult. Participants told us that talking to others for the first time sometimes felt “awkward” because other people “*didn’t know how to interact*” with them. Harry explains how his muscle weakness means he cannot lift his hands to greet people:

“I can’t shake their hands because that happens so often, when somebody comes wanting me to shake their hand, and it’s like an awkward minute or two so there’s that.” HARRY

Participants told us how difficult it sometimes was to feel like they “fit in” with others. This meant that participants sometimes felt they needed to do things like try and walk, even though doing so was very painful.

“I kind of tortured myself and walked to a point where I’d be burning, and I’d just push through it every day because I just wanted to prove something. I felt I had to be... I had to feel normal, even though I was.” JUDE

“I’d say you’d have to deal with a lot more things than most normal people would.”

OLIVER



5. Staying Connected

A key space where participants felt like they could really be themselves was powerchair football. Participants told us that engaging in powerchair football meant they could meet others, develop friendships and romantic relationships, and achieve feelings of success through winning games and tournaments.

It is important to say that some participants spoke about how things had improved for them, things had improved in recent years. However, most participants felt that lots still needed to be done to make them feel part of society, and not pushed aside.

“A lot of friends I keep in touch with through playing powerchair football, some of my teammates.”
FRANCIS



Valuable Findings

(on DMD community, services and policy)

1.

Feelings of uncertainty, anxiety and fears around discrimination about the future are common experiences for young people after finishing education. We need better psychological support to help with adjustment during this transition. Clinical teams should ask how we are coping emotionally, and be able to refer for support.

2.

Being a confident person and having a sense of confidence in certain situations was something participants believed to be important for many different situations experienced when entering adulthood. Strategies developed in childhood and adolescence could help young adults develop their confidence. This could help to improve outcomes for adults with DMD.

3.

Physical changes that can reduce people's abilities to carry out their normal activities can lead to a sense of frustration. Participants identified different ways to help manage how they thought and felt about these changes. Having access to a supportive community to share experiences with others who have similar lived experiences is often helpful. We also believe that improved access to assistive technology is needed for people to be actively engaged in society.

4.

The meaning of independence is unique to each person, and independence can be recognised in many different ways by how people choose to live. This includes access to flexible services (direct payments with efficient support) and housing/ opportunities that enable adults to live a life of their choosing. Feeling independent can be supported through social care, accessibility, and meaningful involvement in care decisions, such as support and funding in managing direct payments, personal assistants, and housing. Likewise, more needs to be done to improve access to buildings and transport to enable independence.

Findings Summary

Our research shows that many young adults approach adulthood with motivations to live an enriching and purposeful life, whether that be through educational achievements, employment, developing hobbies and skills or starting a family. Unfortunately, much like the previous research done over a decade ago, our research shows that achieving this kind of life as an adult can be challenging and demanding. We have highlighted plentiful areas that could be improved to help those approaching adulthood (as well as those who are already adults) living with DMD. This includes better psychological support, access to flexible care and assistive technology, and encouraging other researchers to put greater effort into co-produced research.



What's Next?

Pathfinders will provide information sessions for young people and those supporting them through the transition to adulthood. Sessions will be informative and allow young adults to express their thoughts and feelings around the findings of this research.

The research team will continue to share knowledge gained through this project with other researchers globally. Developing a greater understanding of the issues identified will be helpful in developing improvements to transition for future generations.

In the meantime, the findings from this project will influence the work of Pathfinders and other charities. We hope that this provides support to young adults living with DMD today.



How to Keep up-to-date with the project

1. Sign-up to the mailing list and become a member
 - o www.pathfindersalliance.org.uk
 - o www.pathfindersalliance.org.uk/join-pathfinders
2. Follow our social media pages
 - o www.facebook.com/PathfindersAlliance
 - o twitter.com/pathfindersnma
 - o www.youtube.com/@pathfindersalliance
3. Contact us via email if you would like to become a peer researcher or collaborate your research project with Pathfinders
 - o info@pathfindersalliance.org.uk
 - o suzanne@pathfindersalliance.org.uk

Afterword by Professor Ros Quinlivan

*(MRC Centre for Neuromuscular Diseases,
National Hospital for Neurology and Neurosurgery)*

Pathfinders are to be highly commended for this piece of research which gives a valuable insight into how it feels to be an adult living with DMD and the specific challenges they and their families face. Despite numerous published documents, transition policies and disability discrimination laws, this research highlights the challenges that continue to exist due to a woeful lack of support from education, health, social services and employers.

On a more positive note, the study shows resourcefulness, determination and positive attitudes of the adults interviewed, especially by those who had, or were attending university, even though they faced many challenges. They highlight the importance of friends and family in helping them to live a good life. The adults define what independence means to them and ask that people see and support them in a positive light to help them achieve their full potential, something that is often lacking in schools and the workplace leading to significant feelings of frustration. Independence to an adult with DMD means being autonomous and in control of making one's own decisions. It does not necessarily equate with living away from home but rather living where they choose to live while receiving the physical support they need, delivered by the carers they choose, rather than those thrust upon them.

The participants in this study highlight the many positive skills and attributes that could be developed in adolescents through appropriate transition support that is currently lacking. In particular, developing self confidence of the adolescent is seen as highly important in giving them the power to speak up. They highlight the importance of being able to access psychological interventions to help them manage the many challenges, stresses and anxieties they feel and encounter.

This report also demonstrates how society as a whole must also change. It is shocking to hear how schools, hospitals and employers continue to judge a person with DMD's intellectual capacity by their physical appearance and how young adults with DMD experience discrimination, stigmatisation and bullying.

Politicians should take note of the lack of progress in this area and drive change through funding and tighter legislation.

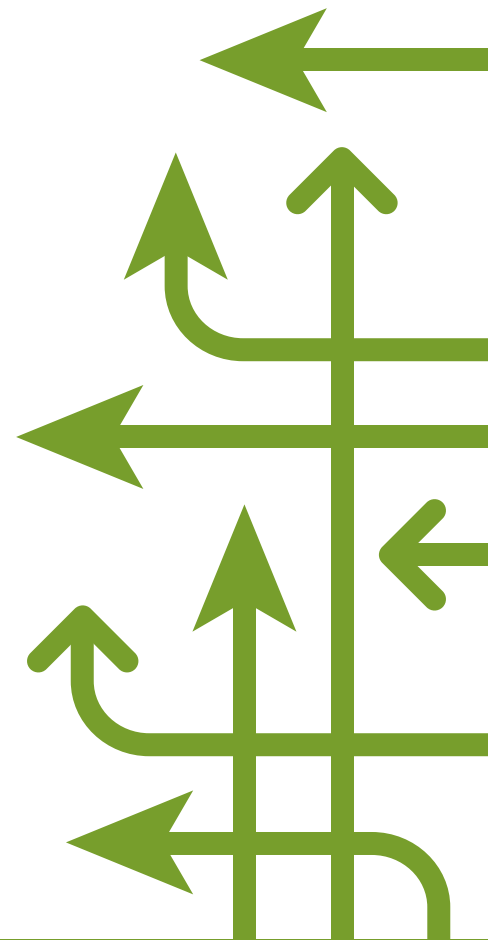
Acknowledgements

First, we would like to express our deepest gratitude to the research participants who generously gave their time and energy to share their personal thoughts, experiences, and future plans with us. We hope their voices are clearly represented in this report.

We also wish to acknowledge and remember the individuals who committed themselves to improving the lives of people with muscle weakening conditions, forming the basis of Pathfinders Neuromuscular Alliance (formerly DMD Pathfinders). Their pioneering work laid the foundation for our organisation.

Contributor Details

- Authors: Dr Suzanne Glover, Jamie Hale (CEO, Pathfinders Neuromuscular Alliance), Matthew Roberts, Jack Bosanquet and Ryan Dack: Pathfinders Neuromuscular Alliance. Dr Janet Hoskin: University of East London, Dr George Peat: University of York and Prof David Abbott: University of Bristol.
- Afterword by Professor Ros Quinlivan: MRC Centre for Neuromuscular Diseases
- Katy Etherington: Freelance Design
- Quinn Clark: Editor



Join Pathfinders

As an organisation, Pathfinders is led by our members – and we offer all sorts of exclusive benefits, from online peer support spaces to advocacy and advice services and community events.

To join Pathfinders, please go to our website or scan the QR code below:



