



Independence - is it '*just a different approach*'?

Independent Living NI Event

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Session Outline

- Introduction: Pathfinders Neuromuscular Alliance
- Background: What do we know about Duchenne Muscular Dystrophy (DMD) and adulthood?
- Key consideration: Independence – is it *‘just a different approach’*?
- Discussion and questions



Introduction to Pathfinders



An organisation run by and for adults with muscle-weakening conditions



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STAFF



TRUSTEES



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Introduction to Pathfinders



Duchenne Muscular Dystrophy

- DMD is a genetic condition.
- Typically, DMD manifests in early childhood.
- The dystrophin deficiency causes a gradual decline in muscle strength.
- This decline often affects the heart, mobility and breathing, requiring increasing assistance.
- Advances in treatment and support have allowed individuals with DMD to live longer into adulthood.



What do we already know about transition to adulthood?



- Improvements in life expectancy have generated subsequent challenges and opportunities for people with DMD.
- The process of transition is often overly medicalised
- A smooth transition to adult health and social care is rarely a reality.
- Research on transition is often situated within the normative expectations of successful transition.

Recruitment of Participants, Data Collection and Analysis

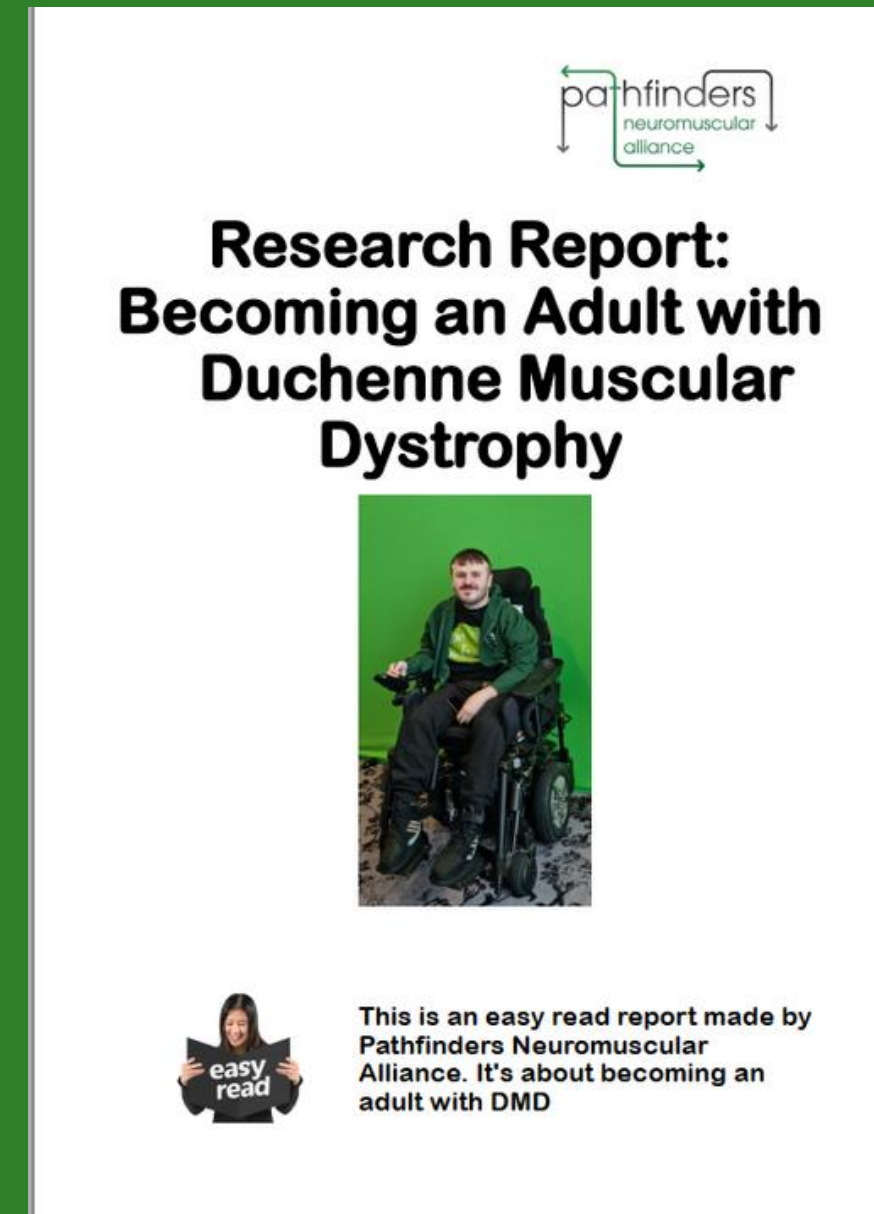
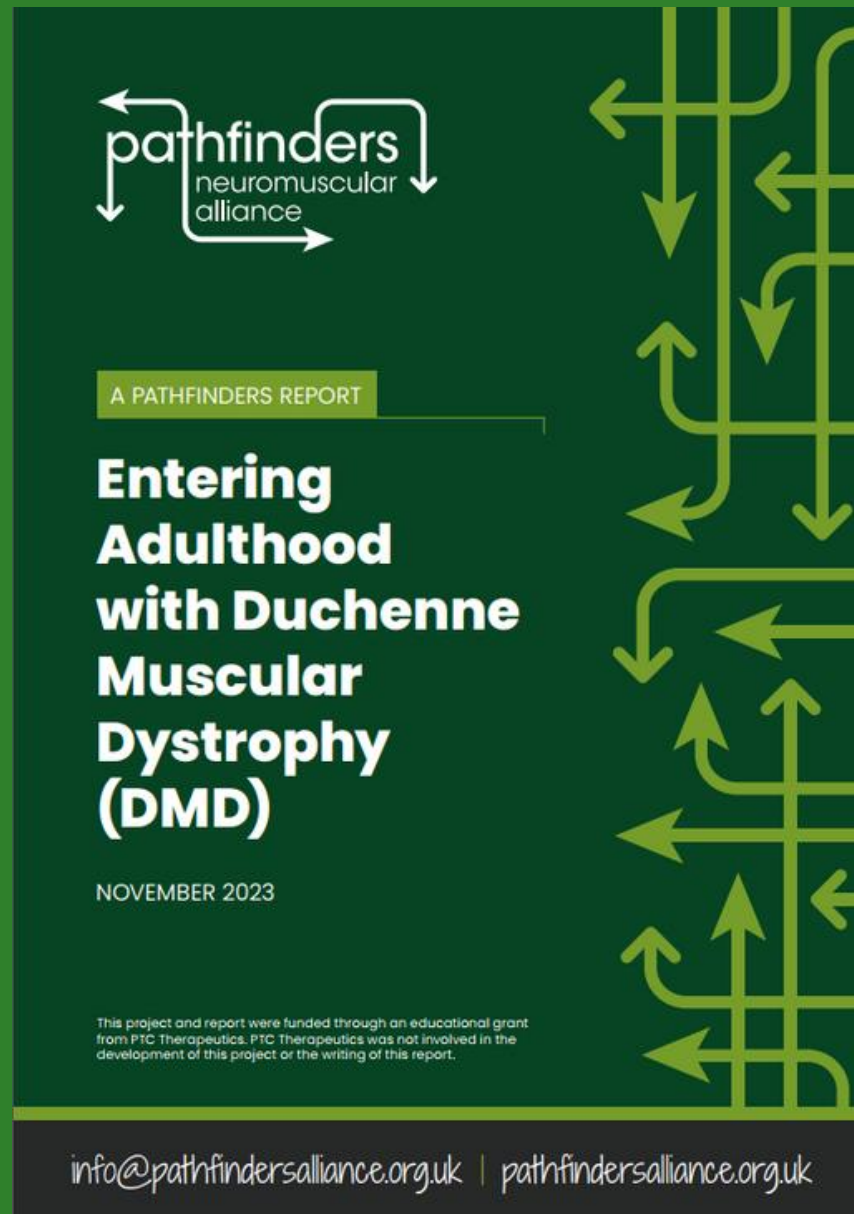


- Peer researchers played an active role in recruitment
- 15 interviews conducted October 2021 – January 2022
- The majority of participants and peer researchers were aged between 25 – 30 years old
- Peer researchers worked with the academics to analyse data and produce the report

Introduction to Pathfinders



Today is the launch of our latest research report.



Independence is...

... a subjective experience

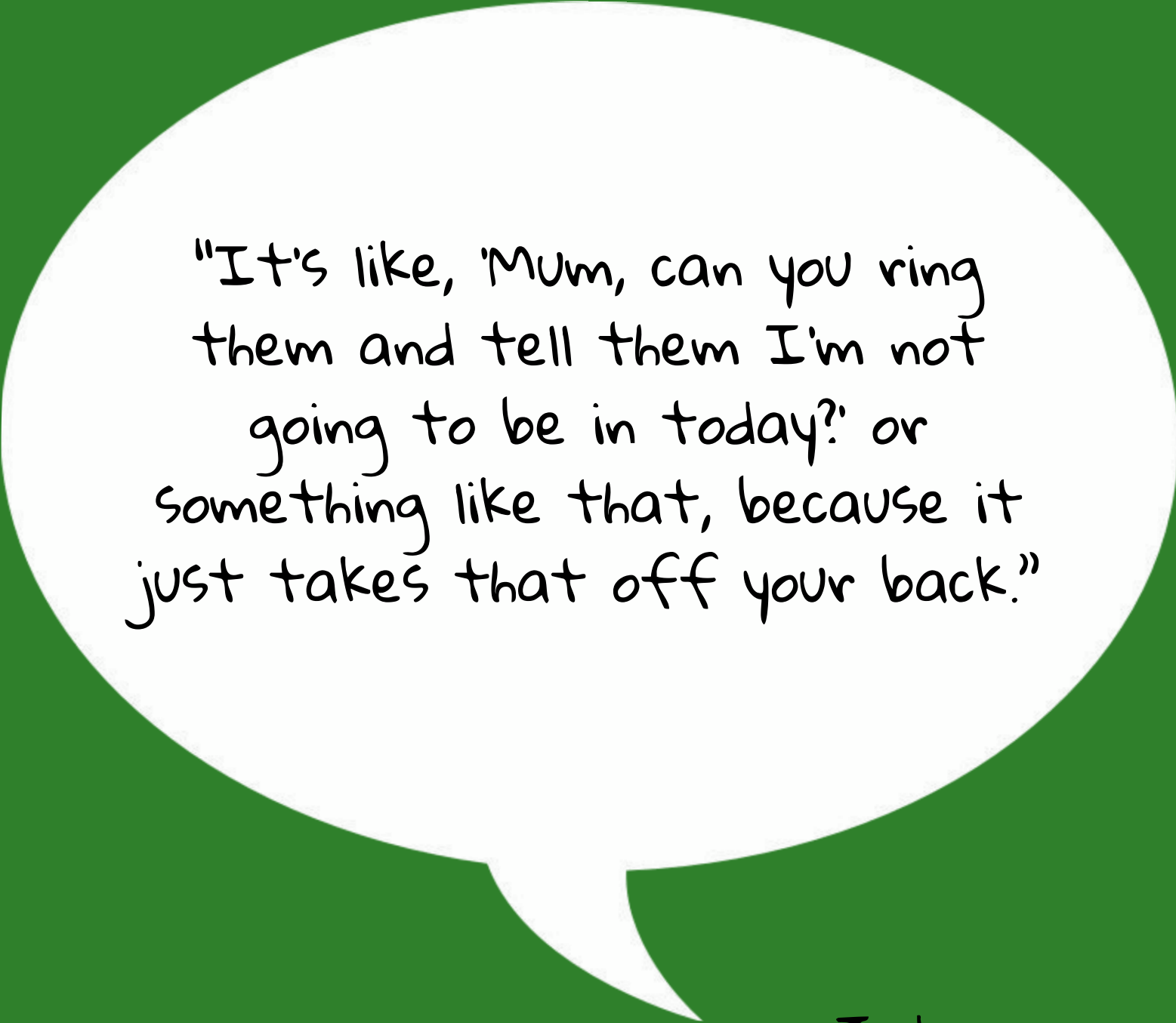
"I always thought that me not moving out was a lack of independence but really it's not, it's just a different approach to things, I guess".

Francis

- Independence meant lots of things different things to different people
- Having choice and control in daily life was important to most adults

Independence is...

...having supportive parents



"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

- Supportive parents encouraged young adults to make their own decisions
- Parents also advocated when needed. This helped young adults to better manage their energy conservation

Independence is...

...having good relationships with carers/PAs

This means:

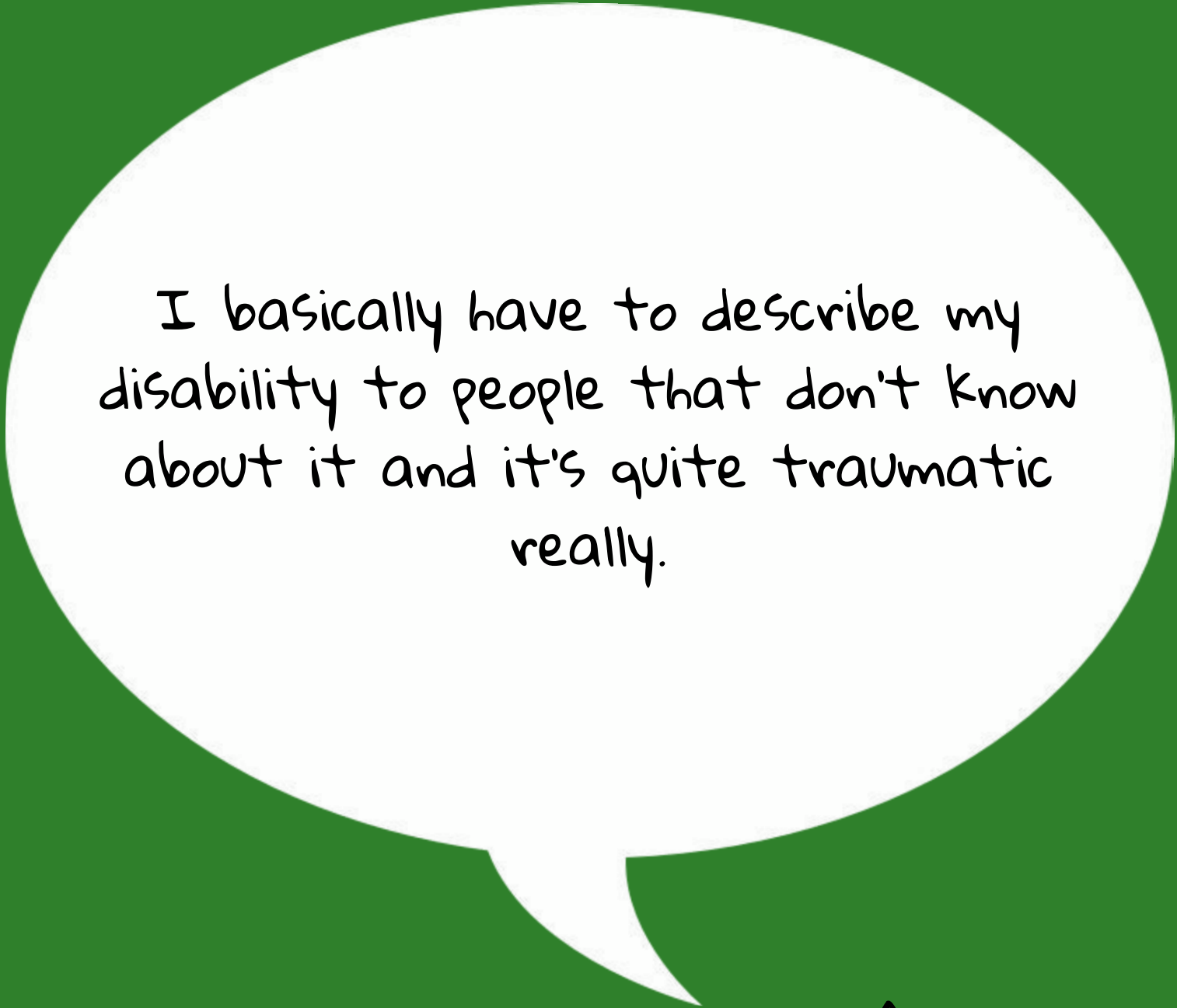
- regular and consistent care
- empathetic carers/PAs
- understanding of the condition
- commonalities and shared interest with carers/PAs

"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"

Sebastian

Independence is...

...a support system and care package (that work!)



I basically have to describe my disability to people that don't know about it and it's quite traumatic really.

Ada
m

- Assessments for care were described as incredibly stressful.
- Some people described the process as becoming more difficult, year after year.
- For those that went to university, support was cut back when they returned home.

Summary

- Our research presents alternative conceptualisations of independence that are often ingrained in our social norms.
- There are many factors that support and hinder individuals being independent.
- Social care should help to facilitate independence beyond providing care funding.



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