

Title: Troubling norms? Adults and teenagers with a life-limiting impairment in Denmark and England talk about their lives, support and future plans

Dr Janet Hoskin

Cass School of Education and Communities

University of East London, UK

Orcid ID: <https://orcid.org/0000-0002-6426-1280>

Contact: [j.hoskin@uel.ac.uk](mailto:j.hoskin@uel.ac.uk)

## Abstract

There are an increasing number of young people with a range of life-limiting impairments in our schools, colleges, universities and communities. One of these impairments is Duchenne Muscular Dystrophy (DMD), a life-limiting genetic muscle-wasting impairment that affects predominantly males. Twenty years ago, those with DMD did not live past the age of twenty years, but due to a range of treatments are now living longer, although education and social care services are often yet to catch up with their improved prognosis. The aim of this paper is to compare the findings from structured conversations with members of the DMD community in Denmark and England. Historically, adults in Denmark have reported a good quality of life with an optimal health care programme and generous social care, whereas adults with DMD in England have reported poor transition to adulthood planning leading to social isolation as an adult. Findings identified three key themes: the existence of normative goals; expertise from lived experience, and the meaning of independence for someone with a complex impairment. These themes are further discussed through the lens of post-human thinking.

Key words: Life-limiting impairments; Duchenne Muscular Dystrophy; normalisation; independence; disHumanism; Transition to Adulthood

## Introduction

Young people with a range of life-limiting impairments are now living longer lives (Fraser 2010). This has important consequences for education, health and social care professionals who work with these young people. One such impairment is Duchenne Muscular Dystrophy (DMD), a severe muscle-wasting condition that is caused by a fault on the dystrophin gene, one of the largest genes in the human genome. As the dystrophin gene is on the X chromosome, DMD it is a predominantly male impairment, affecting one in three thousand male births (Emery & Muntoni 2003). Typical progression is muscle weakness leading to the loss of ambulation by the age of thirteen years (Bushby et al 2010). Historically, young people with DMD did not live past the age of twenty years, but with treatments including cardiac monitoring and ventilation, many men are living longer and some into their thirties and forties (Landfeldt et al 2015).

The improved prognosis of men with DMD has been attributed in particular to the introduction of ventilation in the late 1980s (Rahbek et al 2005). In Denmark, once they progress from requiring only night time ventilation to day-time ventilation as well, men with DMD choose to have invasive intervention which means a tracheostomy. This contrasts with protocol in England and the United States of America (U.S.), recommended in the International Care Considerations (2018) which is produced predominantly by clinicians in the United States of America and England, that strongly recommends non-invasive ventilation, usually using a ventilation mask (Birkbrandt et al 2018).

The aim of this paper is to compare the experience of young adults with DMD in Denmark, with teenagers and young adults with DMD who were part of a ‘Transition to Adulthood’ project in England called ‘Takin’ Charge’, and two adults who were members of the project steering committee. Despite improved prognosis for men with DMD due to treatment such as ventilation, young adults across the world are still often described as marginalised and unanticipated (Eagle et al 2007; Rahbek et al 2005). Furthermore, the main focus of international research in DMD continues to be on medical needs rather than wider issues such as quality of life, education or access to work or leisure (Abbott et al 2019; Gibson et al 2013).

There are distinct differences between Denmark and England with regard to socio-economic and political context. Historically, Denmark has been based on ideals of social democracy and progressive models of citizenship (Baeten et al 2015). This has involved an emphasis on high taxation, state ownership of organisations and equality in pay (Hodgson 2018). Emphasis has been on how society can remove barriers to living well, which is enabled by what has been described as generous welfare legislation. In the case of DMD this means round-the-clock support from personal assistants and adequate benefits for a decent standard of living (Dreyer et al 2010; Rahbek et al 2005 p 18).

In contrast, England has been described as a neo-liberal state that views individuals through their relationship to the market and their ability to contribute as an ‘economic maximiser’ (Lynch 2011). In this system, disabled people can often be depicted as ‘non-marketable commodities’ particularly in the marketplace of schools and colleges (Blackmore 2000). Furthermore, the past ten years of austerity in England has led to more precarity for disabled

people, who have been targeted in cuts to benefits and local services (Bates et al 2017; Duffy 2013;)

The comparison between Denmark and England however has become less binary since the World Banking crisis of 2008, as Scandinavian social democracies have moved towards more neo-liberal elements of Government such as the privatisation of national institutions, and more locally organised welfare (Baeten et al 2015).

Research from both Denmark and England has highlighted that despite an improved health prognosis in both countries, men with DMD often struggle to find employment and relationships (Abbott et al 2013; Rabek et al 2005). In some cases this could be due to lack of expectation, and particularly in England, planning and support during Transition to Adulthood has been reported as inadequate (Abbott et al 2012; CQC 2013). Some have argued that despite lack of resources disabled young people in England aspire to normative aspirations and have similar hopes and dreams with regard to their future employment as their non-disabled peers, and the recent changes in legislation have aimed to support these claims (Legislation.gov.uk., 2014; Sayce 2011) Others however, criticise these reforms for focusing primarily on the economic needs of a neo-liberal society rather than the personal aspirations of young people with SEND themselves (Burch 2018).

Using a Bourdeusian approach to explore the lives of adults and young people with DMD in Canada, Gibson suggested that in order to gain social acceptance, those with DMD choose to minimize their differences with their non-disabled peers (Bourdieu 1984; Gibson et al 2007). These young people appeared to accept what Priestley calls ‘normalized benchmarks of success’ such as academic qualifications, residential independence and employment, aiming to create what Gibson has termed a ‘narrative of non-difference’ between themselves and their non-disabled peers.

Another way of viewing this ‘narrative of non-difference’ could be through the lens of ‘post-humanism’. According to Braidotti, post-humanism offers a critique of how humans have been traditionally understood and depicted. Normative humanism is male as well as ‘white, European, handsome and able-bodied’ (Braidotti 2013; 24). Liddiard asserts that in Critical Disability studies, humanism is a ‘key element’ of ableism because it emphasizes the importance of self reliance, autonomy and independence (Liddiard et al 2019 p 1478).

Using this post-human approach Goodley and colleagues' have developed their 'disHuman' framework, which on the one hand recognizes the importance of normative humanism for disabled people in the 'pragmatic and political value of claiming the norm' that can mean gaining human rights, autonomy and legal protections (Goodley et al 2016 p771). On the other hand, disability can disrupt the normative by moulding and challenging conventional aspirations. Furthermore, Braidotti suggests that this can help us to think creatively and critically about what we are as humans in the process of becoming. (Braidotti 2013; Goodley et al 2016).

These are issues that will be explored and discussed through findings from the DMD Community in both Denmark and England in this paper.

.

### **Method and Materials.**

This paper brings together data from Denmark and England, and centres on hearing the voices of the young people and adults with DMD. It aims to compare experiences of young adults with DMD living independently in Denmark, with teenagers and adults with DMD who were part of a project in England. Although it is acknowledged from the outset that comparing the experiences of varying age groups may limit the findings, the study is significant in that young people with DMD are living longer for the first time, and this impacts on both adulthood and on the period leading up to it when preparations for adult life are being made. Furthermore, it is helpful to understand why for men with DMD the experience of adulthood in Denmark has been reported as positive in literature, whereas Transition to Adulthood (and adulthood) in England has been described as poor and lacking in expectation (Abbott et al 2012; Rahbek et al 2005). With new SEND legislation in England, through which young people are expected to be aspirational about their future, it is particularly important now to learn lessons from other countries where young people with DMD may be achieving more fulfilled lives (Legislation.gov.uk, 2014).

Ethical approval was gained from the University of East London Ethics Board. As a qualitative study, the author adopted the assumption that knowledge is developed through the subjective experiences of people which as Cresswell notes, involves conducting studies 'in the field where participants live and work' (Cresswell 2013 p20).

Danish participants were recruited through the rehabilitation hospital in Aarhus, Denmark, which shared information with patients, and six adults self-referred, as did a doctor from the hospital. Five of these participants took part in semi-structured interviews in their homes, one was interviewed at his place of work and the doctor was interviewed at the Muscle Foundation at Aarhus. Two adults with DMD from England, who had been members of the steering committee for Action Duchenne's Takin' Charge Transition to Adulthood project, gave signed consent and took part in semi-structured interviews in their homes through Skype. Young people with DMD aged 14 – 19 years in England self-referred through the Takin' Charge project that was delivered in various venues across the UK, mainly in hospices. Data was collected from the young people through three focus groups that took place in hospices in Luton and Midlands and at the charity's international conference in London.

Initially it was hoped to carry out semi-structured interviews in line with the adult participants, but as many of the younger participants reported themselves as shy, it was felt that focus groups could help to enable longer discussions and make participants feel more comfortable in sharing their views. All participants gave signed consent, those under the age of 16 years gave signed assent along with their parents' signed consent. (BERA 2018). All interviews were conducted in person or via Skype by the author; focus groups were led by two Takin' Charge support workers in partnership with adults with DMD at the end of a Takin' Charge event in each venue. All were conducted through the medium of English, audio recorded and transcribed verbatim. Information about all participants and context for data collection is presented in Table 1.

### **Table 1 : Participants and Context for Data Collection**

Acknowledging Oliver's observations on the potential power relations between interviewer and participants, all questions in both the semi-structured interviews and the focus groups used concepts from Solution Focused Brief Therapy (SFBT) (De Shazer & Dolan 2007; Oliver 1994). SFBT is built on 4 premises: firstly look for resources a person has, rather than deficits; secondly, explore the person's possible and preferred futures; thirdly, identify what is already helping towards those futures and finally, recognise that the participant is an expert of their own life (Ratner et al 2012). Therefore questions focused on what worked in people's lives, how they had managed to achieve this, rather than searching for what had not worked

and making the interviews an alienating experience which could situate the ‘problems’ facing disabled people within the individual (Oliver 1994).

Conversations began with the following questions about which participants were asked to elaborate: for the Danish and English adult participants ‘What are you pleased to notice about your life now? What has it taken from you to achieve that? What are your best hopes for the future?’ For the young people (aged 14 – 19 years) in the Takin’ Charge project: ‘What were you pleased to notice about the Takin’ Charge project? What did it take from you to engage with this? What are your best hopes for the future?’

The author is the parent of a young adult in England who has DMD, which gave her good ‘insider’ knowledge and helped to create a relationship of trust during interviews (Stevens et al 2010 ) However, it was crucial that she was self-reflexive and did not let prior assumptions colour her design and analysis. To this purpose she worked with a small number of adults with DMD from a user-led organisation who helped to develop questions and discuss findings.

The data from both countries was interrogated together, and shared themes were identified using Braun and Clarke’s 6 stage iterative approach. The researcher familiarised herself with all of the data before creating codes that were revisited and adapted through various readings and discussions with a small steering group of men with DMD (Braun and Clarke 2006).

The final themes that emerged from the data were:

- Having normative aspirations
- Expertise from ‘lived experience’
- The meaning of independence for someone with a complex impairment

All participants’ names have been changed to enable anonymity.

## **Findings**

### **Theme 1: Having Normative Aspirations**

In Denmark, findings indicate that the adults interviewed had all been supported to achieve normative benchmarks of adulthood such as employment and independent living. The Danish participants appeared to view these milestones as part of ‘normal life’. With regard to employment, all of the six adults with DMD interviewed were either working or following courses that would lead to paid or voluntary work. For example, one participant (William) was working full time in an IT job, another (Matthew) was a civil engineer who had helped to design the building where our interview took place. Matthew spoke about his job:

*‘I’ve never really thought about it. It’s just the next step in life.’*

However, he stressed the importance of ‘*realistic work opportunity*’.

This need for realistic ambitions was echoed by William who was talking about how he was working in IT and Game Design :

*‘I mean you can’t help but be a little bit affected by knowing that there are certain things that are not possible. I want to be a footballer yeah sure. So I think some of it just made sense in the first place....’*

Oliver was at university studying to become a curator in a museum. Victor was just starting his training to be a social worker and Tomas had been working as a life coach and currently was volunteering. Finally, Joseph was about to begin a masters degree in philosophy. Both the latter two were also involved in setting up a user-led organisation to oppose voluntary euthanasia.

A fundamental aspect of having a ‘normal life’ is the opportunity to socialise and have relationships. Oliver and Victor, in particular spoke about the importance of being able to socialise with their friends. Victor said he went out weekly with a group of friends who stayed at his place after they had been to the local bars. Oliver spoke about music gigs he liked to attend and reported that even though he was enjoying his course *‘the most important part of life is the social part.’*

Only one of the participants, William, was in a relationship, and he shared his flat with his girlfriend. They had plans to go travelling to New York in the future, but as he stated, having



Duchenne ‘*made it difficult to backpack*’ as everything needed to be well organised beforehand. This suggests his adherence to normative expectations of young adults in their twenties who go travelling, but also an acceptance of a different reality with a physical impairment.

Tomas explained that sex and relationships was an area that the state acknowledged was problematic for men with DMD and for which services were provided. He talked about how young adults in Denmark were offered ‘*advisors of sexuality*’ who ‘*can actually go to a disabled person and talk about – you name it- sex toys and the practicality of it but also the feelings and what about your PA (personal assistant) if I got a girlfriend and so on.*’ He also talked about the widespread use of sex workers in Denmark.

Throughout the interviews with the Danish participants the phrase ‘*a normal life*’ appeared frequently. Phrases like ‘*an ordinary family*’, ‘*normal activities*’, ‘*regular school*’, ‘*inclusive*’ came up often. Most participants talked about their families being responsible for shaping their expectations and supporting them to get what they needed.

Having a ‘normal’ life also appeared to mean that the Danish participants did not want their lives medicalised. Although physiotherapy is offered twice weekly in Denmark, several of the Danish adults were ambivalent about it.

*‘I think it has actually helped my quality of life to not have that.’* (Joseph)

Tomas agreed saying:

*‘I wouldn’t say don’t do training and don’t do these things but I would say do it moderately because the most important thing is that you get a life.’*

In contrast to the experiences of people with DMD in Denmark, findings from the focus groups in England suggested that young people with DMD are not being supported to have normalised expectations for their lives. Few of the teenagers had really thought about what their futures might look like. This shows in their evaluation of the Transition to Adulthood project:

*‘It (the transition project) has been interesting and inspiring – I didn’t know what’s possible in terms of a good life as an adult. I feel I have moved on’*

Another participant talked about how it *‘opened my eyes’* and that he could see *‘so many new things that I didn’t imagine possible’*.

One participant said that through the project *‘I have realised I have choices’* which the group agreed with. Likewise, another participant reported that the best thing about the project was: *‘I have found out stuff I wouldn’t have found out otherwise’*.

This suggests that services in England may not be supporting young people with DMD to access appropriate support that can enable them to strive for or achieve normative goals.

Each of the English focus groups discussed ideas about getting a job and many said it was something they were now considering. Some of the older members who had not achieved many qualifications spoke about the option of self-employment which they had not contemplated before. This was confirmed in the interview with David, the adult from England:

*‘Absolutely nowhere else is doing this. Like you know if a person with DMD went anywhere else they would just be told they shouldn’t work, just not bother basically, so I think that it’s been vital to look at this.’*

Many of the boys talked about how meeting older men with DMD had helped them realise the possibility of working and living independently, and how having a personal assistant became normalised rather than something other people did. As one young person said *‘meeting the men with DMD made me want to sort out my budget and have my own PAs’*

In comparison to Denmark, lack of ambition and low expectations from services appear to have been the hallmark of experiences for adults with DMD in England. Lewis who was 46 years old at the time of the interview explained that when he was 24 he had been very ill and when he spoke to the doctors

*‘they told me not to expect to live much longer because I had a serious condition.’*

After this he spoke to his doctor about having a tracheostomy, and he reported *'getting a new lease of life'*.

With regard to decisions he had made as he was growing up he said:

*'I would have planned ahead a bit more I think....I might have ended up working.'*

David echoes this lack of planning for the future:

*'I'm not saying I necessarily did stuff that I wouldn't have wanted to do it's just there were compromises that I made on the basis that I wasn't going to live very long.....'*

Making friendships, was reported by all of the focus groups as one of the driving forces for joining the Transition project. All participants agreed that workshops on sex and relationships had been an important aspect of the programme, although all were reticent to discuss much further, perhaps suggesting that this is still a taboo subject for many disabled young people in England. In contrast to findings from Denmark, one young person said:

*'no-one is having the conversation and saying that boys with my condition can get girlfriends'*

Again, this seemed to be something that had not changed much between generations of men with DMD, as Lewis reported

*'when I grew up it was something very much that was missing and I think that very much affected me'*.

## **Theme 2: Expertise from 'lived experience'**

The notion of 'lived experience' has become popular with social policy researchers in a wide range of areas (Macintosh and Wright 2019). In this paper, the term is being used to describe the experiences and opinions of those who live with DMD in contrast to the expertise of professionals.

In Denmark, the voice of those with lived experience of DMD was assumed crucial to enable best medical practice. The neuromuscular doctor emphasized how the experience and expertise of the men with DMD had shaped the way in which they provided health support for people with neuro-muscular impairments. He said of the adults with DMD:

*'they were the first generation ever with Duchenne to become adults so it was very difficult for us to tell them about how it is to have Duchenne when you are grown up....so we have had to find out that together.'*

He went on to explain:

*'(in the past ) all the doctors told the parents and everybody that it is not a life to live to be using a respirator... we said we wanted to try it, we had never seen anyone trying it, and we thought, perhaps it's a good life.'*

When asked about the choices of respiration in Denmark he replied:

*'When a boy with Duchenne asks me should I have one (a tracheostomy) I say: I don't know. I say you can talk to the older people and ask them how is it, and they all say it is much, much easier than having a mask.'*

Tomas also discussed respiration and talked about meeting doctors who were experts in respiration at an international conference:

*'According to those American doctors, it's not a dignified life (having a tracheostomy)...and they continue saying that you can't sing and you can't talk with one. Even though my soulmate S who lives upstairs has a trachie, and she won the Danish X Factor (a national singing competition).'*

Two of the Danish participants (Tomas and Joseph) were sharing their expertise with the wider Duchenne and disabled community, and had recently set up an organisation 'Not Dead Yet', linked to the group with the same name in the US, in order to oppose the recent popularity of voluntary euthanasia in Denmark. Joseph described their organization as

*'politically aggressive.... It's really about educating people how you can get a good life even with a disability'*

None of the other Danish participants spoke about the need to meet up and learn from other DMD adults. However, all agreed on the important work of the Danish Muscle Foundation in supporting people with DMD even though they did not tend to go to organized events.

In contrast, all of the English focus groups reported that being able to meet and listen to other people with DMD through the project, swap experiences and hear from the adults with DMD was one of the key motivations for joining. As one participant put it: *'I was keen to meet people who understood my challenges'*.

For the teenagers in England, meeting and learning from adults with DMD was a crucial aspect of the project. One participant reported that for him the most important factor was *'knowing there are older men with DMD who live independently'* suggesting that this was something that wasn't common knowledge. He added that *'for the first time'* someone had explained *'how they had got their budgets and their houses and things.'*

Much of the discussion in the focus groups showed that teenagers particularly valued learning from older adults with DMD how they too could organize their lives, implying that this was not something they were learning as a matter of course.

As in Denmark, the adults with DMD, Lewis and David, had set up their own England-based user-led group and were now sharing their lived expertise with the wider community.

David remarked;

*'My expectations of the (Takin Charge) project have definitely been exceeded, just in terms of what the steering committee has done in getting adults more organized and having a voice...if you had told me that we'd have been setting up a charity for adults when we started I wouldn't have believed you.'*

### **Theme 3: The meaning of independence for someone with a complex impairment**

In Denmark, all of the participants with DMD were living independently away from their families – which is as Victor reported *‘the norm in Denmark.’* He went on to say *‘I’m happy that I can get to really live on my own and have control of my own life.’* Others have spoken about how men in Denmark view themselves as independent despite needing twenty four hour support, as they are able to make choices, this has been termed *‘independent dependence’* (Dreyer 2010)

Notwithstanding, all participants spoke about the importance of family, and five out of the six participants lived within 30 mins away from their families and saw them weekly. Several of them reported that their parents had helped them to advocate for what they needed. On the whole all adults in Denmark all reported they were able to live well from day to day suggesting that they do not feel the precarity that has been linked to young people with DMD and families in England previously (Hoskin 2019) and other disabled people in the UK (Goodley and Runswick-Cole 2016; Bates et al 2017).

The most challenging aspect of living independently in Denmark was reported as managing a care team. Matthew said: ‘

*The biggest concern and the most annoying part of being in a wheelchair is to manage having the helpers, to figure out when one is sick and how do we do in in another way so that I get one that is equally good and also getting them to stay many years so its not shifting around all the way.’* Matthew was 34 years old and had moved out from home 12 years ago. :

*‘I dare not count how may guys I ‘ve had working under me but it’s probably 60 or 70’*

The priorities and concerns of the participants in England around independence were quite different to the Danish ones. In England, physically moving away from the family home did not appear to be something that many in the focus groups had considered, although David and Lewis from the steering committee both lived alone with the support of personal assistants. David and Lewis expressed their disappointment that despite this being a key part of the Transition project, few young people had made firm plans to move out. Nevertheless, the project appeared to have given the young people with DMD information and ideas on how to go about living independently and how to budget.

For example, comments like *'I'm Thinking about moving out'*, *'I might move out on my own now'* and *'I feel more confident doing more things on my own now'*, suggested that teenagers with DMD now viewed independent living as an option for their future, which they may not have considered before.

In discussing this David said:

*'I think it's one of the hardest things to encourage someone to do (live independently) and I'm not necessarily saying it's the only option...my only worry is that when Takin Charge ends they'll settle in to just being at home and looked after by parents and not think about moving out.'*

But as Lewis noted:

*'some people may choose to stay with their parents but it's really their transition and that means that they can still stay in control'*

Beginning to allow carers to start doing things instead of parents was seen as an immediate priority by all groups. As one young person said:

*'it's made me think about not just relying on other people'*, and another talked about the importance of *'doing more things on my own.'* Perhaps the most telling comment came from a young person who said:

*'The sessions have made me more confident about speaking and knowing that Mum and Dad don't need to do everything'*

Discussing this point, David said :

*'It's much easier to think about moving out when you've got an independent care team who you're in control of...so it's not just about housing, that might be the final stage, but an earlier stage is about allowing other carers to do what their parents do.'*

Lewis agreed adding

*'one way of starting it all off (living independently) is talking about needing a bit more assistance. Getting assistance off somebody that isn't your parents can be done slowly and quite gently sometimes 'cos getting a few hours a week for a few years and just to start going out when you're living at home.'*

## Discussion

This paper has presented only limited perspectives of life with DMD that were discussed from a very rich data-set. To some extent, all three themes reflect the differing socio-economic and political contexts, and on the surface it would be easy to compare these findings in terms of Denmark offering a more favourable life for young people and adults with DMD than England. Undoubtedly, the English government's choice of following a damaging austerity programme has radically affected the way in which disabled people, and in particular those with more complex impairments, have been supported to live and plan their futures in England (Duffy 2013; Wood 2012; Ryan 2019). This may indeed explain why the young people with DMD in England were keen to make informal networks to gain information about benefits and opportunities from the 'experts' with DMD as they were not gaining it in any other way. Furthermore, despite changes on the surface of the new SEND legislation in England, the consistent attack on services has meant the removal of layers of professionals who in the past may have had experience in supporting them (Hoskin 2019).

On the other hand, the socio-economic situation in Denmark has changed since 2008, and, although not implementing as severe cuts as England, has begun to embrace some neo-liberal practices within its delivery of its public services (Mailand 2014). In addition, discrimination against disabled people is not exclusive to England, and the fact that Tomas and Joseph felt the need to campaign against the growing popularity of voluntary euthanasia and argue that life with a complex disability is worth living could suggest they felt that not everyone shared their view. Matthew was frustrated with the lack of support in managing and keeping his large turnover of personal assistants indicating that wages and job conditions for carers may not be as favourable as they could be in the Danish care sector.

Using a 'posthuman' lens, it could be argued that despite their socio-political differences, England and Denmark are similar in that both systems are based on a humanist ontology that celebrates a particular type of normative humanity. As the posthumanist Rosi Braidotti has pointed out, 'normative humanity' tends to refer to those that are, white, male and non-disabled (Braidotti 2013 p 24) and excludes anyone who does not meet these 'species typical' criteria (Campbell 2009). Those people who do not fit this criteria become 'other', and according to Braidotti's definition of the human would include other minorities such as women, people of colour, L.G.B.T.Q.+ and disabled people (Braidotti 2013).



As we have seen in this project, participants in both England and Denmark report that achieving normative benchmarks of adulthood such as academic success, employment and residential independence is important to them, following as Gibson puts it, ‘an unreflective pursuit of normal’ (2013 p 16). For example, Matthew’s comment regarding employment saying *‘I haven’t really thought about it. It’s just the next step.’*

Viewing this ‘narrative of non-difference’ through a post-human lens enables us to see the attraction of the normative for disabled people and how important it is to continue ‘to fight to be recognised as humans’, despite daily oppression and exclusion that may occur (Goodley et al 2016 p785). Normative humanity offers human rights, citizenship, legal protections and a sense of belonging. However, post-humanism can enable us to think critically and creatively about what it really means to be human, combining ‘the critique of normative bodily models with the advocacy of new, creative models of embodiment’ (Braidotti 2013: 146). In the case of DMD, models of embodiment can include use and reliance on an electric wheelchair, ventilators that assist breathing, and other assistive technology that can support a person to live a fulfilled life, as well as the interdependent relationship with a personal assistant. Disability can challenge and disrupt the humanist neo-liberal status-quo, particularly as it often demands interconnectedness rather than social isolation and competition between people (Lynch 2011).

As early as the 1980s Oliver noted that ‘no one in modern industrial society is completely independent’ (Oliver 1989 83-4), even though the neoliberal narrative is to stress individualism. Priestly has argued that interdependence can reframe ideas around what it means to be independent, and with regard to men with DMD, their interdependent relationship with both their personal assistants and their assistive technology has been described as ‘independent dependence’ (Dreyer 2010; Priestley 2009). This means that in order to achieve normative goals such as employment or independent living, adults with DMD experience mutually supportive relationships with those who they employ as personal assistants, family members and machines. This therefore disrupts and challenges the way in which humans are expected to live in neo-liberal society.

Furthermore, Goodley and colleagues suggest that disability gives everyone the chance to think about how they want to live and work, rather than simply how they are forced to in a

neo-liberal system, offering ‘opportunities for reconsidering our relationships with life, labour and slow death.’ (Goodley et al 2014 p938)

As the Danish doctor in this project said of the lives of men with DMD in Denmark:

*‘...perhaps it is a good life’*

Several applied recommendations can be drawn from these findings. Firstly, professionals working with young people with DMD in schools, health and social services should be trained effectively in person-centred planning in order to support young people and their families to identify aspirations and agree outcomes for a fulfilled life. They also need to be aware that many young people with DMD are now living into adulthood, and may want to enjoy many of the opportunities and responsibilities that being an adult involves. Amongst other things this means allowing young people to become accustomed to employing personal assistants to provide for their care needs before they become adults. Understanding what is possible for young people with a life-limiting complex impairment is also important and linking families with user-led organisations particularly those that represent adults with DMD can mean access to knowledge of other adult journeys.

However, training alone is not enough to make the changes necessary for better outcomes, and as the recent House of Commons report goes on to say, for things to improve there needs to be a ‘systemic cultural shift’ (Parliament. House of Commons 2019 p 84) in the way children with SEND are viewed and supported so that they are part of Education’s ‘whole approach’ rather than ‘just an add-on’ (ibid p4). This could mean being aware of opportunities for young people of all abilities so that the hopes and dreams of disabled young people and those with complex impairments are taken as seriously as their non-disabled peers. This in turn can begin to challenge our view of the normative, and help us to think differently about ways of living that are based on interdependence and co-operation rather than isolation and competition.

## **References**

Abbott, D., Carpenter, J. & Bushby, K. (2012) ‘Transition to adulthood for young men with Duchenne muscular dystrophy: research from the UK’, *Neuromuscular Disorders* , 22, 445–446.

- Abbott, D., Carpenter, J., Gibson, BE, Hastie, J., Jepson, M. Smith, B., (2019) Disabled men with muscular dystrophy negotiate gender *Disability and Society* : 34: 5
- Baeten, G., Berg, L. D. And Lund Hansen, A. (2015): ‘Introduction: neoliberalism and post-welfare Nordic states in transition’, *Geografiska Annaler: Series B, Human Geography* 97 (3)
- Bates, K., Goodley, D. & Runswick-Cole, K. (2017) ‘Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity’, *Disability & Society* , 32 (2), 160–175.
- Berlant, L. (2007) “Slow Death: Sovereignty, Obesity, Lateral Agency.” *Critical Inquiry* 33: 754–780
- Birnkrant DJ, Bushby K, Bann CM, Apkon SD, Blackwell A, Colvin MK, Cripe L, Herron AR, Kennedy A, Kinnett K, Poysky, J., Street, N., Weber, D.& Ward L. (2018) *Lancet Neurology*. 17(5):445-455.
- Braidotti, R. (2013) *The Posthuman*. UK: Polity Press
- Braun, V. & Clarke, V. (2006) ‘Using thematic analysis in psychology’, *Qualitative Research in Psychology* , 3 (2), 77–101.
- Burch, L. F. (2017) ‘Governmentality of adulthood: a critical discourse analysis of the 2014 Special Educational Needs and Disability Code of Practice’, *Disability & Society* , 33 (1), 94–114.
- Bushby, K., Finkel, R., Birnkrant, D. J., Case, L. E., Clemens, P. R., Cripe, L., Kaul, A., Kinnett, K., McDonald, C., Pandya, S., Poysky, J., Shapiro, F., Tomezsko, J., Constantin, C. et al DMD Care Considerations Working Group (2010) ‘Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and pharmacological and psychosocial management’, *Lancet Neurology* , 9 (1), 77–93.
- Creswell, J. (2013) *Research Design (International Student Edition): Qualitative, Quantitative, and Mixed Methods Approaches*
- DfE (Department for Education) & DoH (Department of Health) (2015) *Special Educational Needs and Disability Code of Practice: 0 to 25 years* [online at <https://www.gov.uk/government/publications/send-code-ofpractice-0-to-25>].
- De Shazer, S. & Dolan, Y. (2007) *More than Miracles: the state of the art of solution-focused brief therapy* . Abingdon and New York: Haworth Press.

Dreyer, P., Steffensen, B. & Pedersen, B. (2010) 'Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation', *International Journal of Qualitative Studies on Health and Wellbeing* ,5 (3)

Duffy, S. (2013) 'Briefing on how cuts are targeted', Centre for Welfare Reform [online at <http://www.centreforwelfarereform.org/library/by-az/briefing-on-how-cuts-are-targeted.html>].

Eagle, M., Bourke, J., Bullock, R., Gibson, M., Mehta, J., Giddings, D., Straub, V. & Bushby, K. (2007) 'Managing Duchenne muscular dystrophy- the additive effect of spinal surgery and home nocturnal ventilation in improving survival', *Neuromuscular Disorders* , 17, 470–475.

Education Select Committee 1<sup>st</sup> Report Special Educational Needs and Disabilities HC 20  
Published 23 October 2019 accessed here on 23 October 2019 :  
<https://publications.parliament.uk/pa/cm201920/cmselect/cmeduc/20/2002.htm>

Emery, A. & Muntoni, F. (2003) *Duchenne Muscular Dystrophy* (3rd edn).Oxford: Oxford University Press.

Fraser, L., Miller, M., Hain, R., Norman, P., Aldridge, J., McKinney, P. & Parslow, R. (2012) 'Rising national prevalence of life-limiting conditions in children in England', *Pediatrics* , 129 (4), e923–929.

Gibson, B. E., Mistry, B., Smith, B., Yoshida, K. K., Abbott, D., Lindsay, S. & Hamdani, Y. (2014) 'Becoming men: gender, disability, and transitioning to adulthood', *Health* , 18 (1), 93–114.

Gibson, B.E., Young, N.L., Upshur, R., et al. (2007) Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy. *Social Science & Medicine* 65(3):505–517.

Goodley, D. (2011) *Disability Studies: an interdisciplinary introduction* . London: Sage.

Goodley, D., Lawthom, R. & Runswick-Cole, K. (2014) 'Dis/ability and austerity: beyond work and slow death', *Disability & Society* , 29 (6), 980–984.

Goodley, D., Runswick-Cole, K. & Liddiard, K. (2016) The DisHuman child, *Discourse: Studies in the Cultural Politics of Education*, 37:5, 770-784,

Goodley, D., Liddiard, K., & Runswick-Cole, K. (2018) Feeling disability: theories of affect and critical disability studies, *Disability & Society*, 33:2, 197-217

Hamdani, Y., Mistry, B. & Gibson, B. E. (2015) 'Transitioning to adulthood with a progressive condition: best practice assumptions and individual experiences of young men with Duchenne muscular dystrophy', *Disability and Rehabilitation* , 37 (13), 1144–1151.

- Hendriksen, J. G. & Vles, J. S. (2008) 'Neuropsychiatric disorders in males with Duchenne muscular dystrophy: frequency rate of attention-deficit hyperactivity disorder (ADHD), autism spectrum disorder, and obsessive-compulsive disorder', *Journal of Child Neurology*, 23, 477–481.
- Hodgson, G (2018) What the world can learn about equality from the Nordic model *The Conversation* accessed here on October 10 2019: <https://theconversation.com/what-the-world-can-learn-about-equality-from-the-nordic-model-99797>
- Hooks, B. (1990) *Yearnings Race, Gender and Cultural Politics* Southend Press
- Ratner, H., George, E. Iveson, C. (2012). *Solution Focused Brief Therapy 100 Key points and Techniques* Routledge London
- Landfeldt, E., Lindgren, P., Bell, C.F., Guglieri, M., Straub, V., Lochmuller, H., Bushby, K (2015) Health-related quality of life in patients with Duchenne muscular dystrophy: a multinational, cross-sectional study *Developmental Medicine & Child Neurology*, DOI: 10.1111/dmcn.12938
- Lynch, K. (2006) 'Neo-liberalism and marketisation: the implications for higher education', *European Educational Research Journal*, 5 (1),
- Macintosh, I. and Wright, S. (2019) Exploring what the Notion of 'Lived Experience' Offers for Social Policy Analysis. *Journal of Social Policy Analysis*. *Journal of Social Policy*, 48(3), 449-467
- Mailand, M. (2014) Austerity Measures and Municipal ties : the case of Denmark *Transfer* vol 20, no.3
- Oliver, M. (1990) *The Politics of Disablement*. Basingstoke: Macmillan.
- Priestly, M. (2003) *Disability: a life course approach*. Cambridge: Polity Press.
- Rahbek, J., Werge, B., Madsen, A., Fynbo, C., Steffensen, B. & Jeppesen, J. (2005) 'Adult life with Duchenne muscular dystrophy: observations among an emerging and unforeseen patient population', *Paediatric Rehabilitation*, 8 (1), 17–28.
- Ryan, F. (2019) *Crippled: Austerity and the Demonisation of Disabled People* Verso London
- Sayce, E. (2011) *Getting In, Staying In and Getting On. Disability employment support fit for the future. A review to Government Department for Work and Pensions*. London: Stationery Office.
- Stevens, M. M., Lord, B. A., Proctor, M., Nagy, S. & O'Riordan, E. (2010) 'Research with vulnerable families caring for children with life-limiting conditions', *Qualitative Health Research*, 20 (4), 496–505.

Wood, C. (2012) *For Disabled People, the Worst Is Yet to Come ..., Destination Unknown: Summer 2012*. London: Demos

**Table 1 : Participants and Context for Data Collection**

<b>Participants</b>	<b>Number</b>	<b>Method and Context</b>
14 - 19 year old males with DMD	7	Focus group in Children's Hospice in Midlands, England
14 –19 year old males with DMD	8	Focus group in Children's Hospice in Bedfordshire, England
14 –19 year old males (YP)	7	Focus group in Action Duchenne International conference in London, England
Adults with DMD members of the Takin Charge project Steering Committee in England (names have been changed) David 36 years old Lewis 47 years old	2	Semi-structured interviews via Skype, UK
Adults with DMD in Denmark (names have been changed) Joseph Tomas Matthew William Oliver Victor	6	Semi-structured face to face interviews at home except William's which took place at his place of work ,Denmark

Neuro-muscular Doctor in Denmark	1	Semi-structured interview at Danish Neuromuscular Foundation, Denmark
----------------------------------	---	---