

# Men living with long term conditions: exploring gender and improving social care

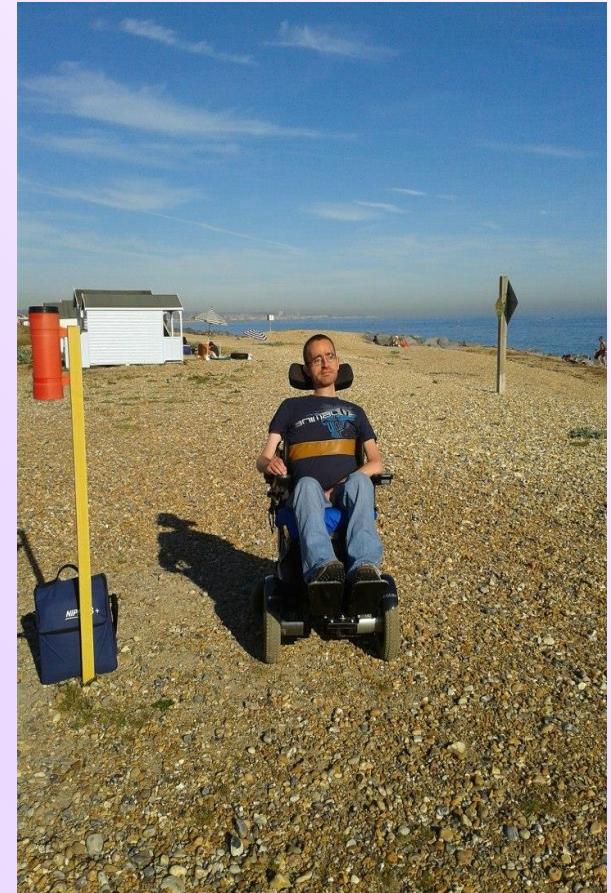


Duchenne Family Support Group  
A support group for families affected by Duchenne Muscular Dystrophy

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Family Support Group

# About the study

1. To understand how men with a long-term and life threatening condition (in this instance, DMD) understand their identity as men and how their gender is, or could be, supported by adult social care professionals.
2. To improve social care professionals understanding of and approaches to issues of male gender when supporting men with long term conditions and thereby improving outcomes for service users.
3. To gain some insight, on a small scale, into how user involvement in research may or may not affect the 'co-production' of talk and meaning in a research encounter (in this instance about gender and living with a long-term condition) – and arguably therefore in other encounters with social care staff.



# Methods

Twenty men with DMD interviewed in 2013. Recruited with support of the Duchenne Family Support Group and via muscular dystrophy related Facebook pages. David Abbott at the University of Bristol carried out two thirds of the interviews and Jon Hastie a researcher and activist living with DMD carried out a third.

A loosely structured interview schedule (sent to participants in advance)

Thematic analysis plus two day round table analysis meeting with:

Prof. John Carpenter (social care)

Dr Barbara Gibson (intersection of disability/male gender)

Dr Brett Smith (narratives of masculinity)

Dr Marcus Jepson (using CA to look at the interviews)

Dr Jon Hastie (inside perspective)

Fine-grain analysis to: explore how the talk and interaction is co-constructed and co-produced between interviewer and interviewee; and, examine the differences in the talk between interviews organised by David and those organised by Jon.

# Participants

- 21-33 years old
- All regions of England (including rural)
- 2 Asian British, 1 South African, 17 white British
- 1 learning disabilities
- 1 father
- 1 gay
- 11 living in parental home; 7 living independently; 2 in residential settings
- 7 buying PAs through PBs/DPs; 6 continuing health care funding; 3 agency staff via LA; 2 onsite residential staff; 2 from family members.



# Headline findings

Social care in its broadest sense did little to support a positive sense of masculinity or male gender (with a very small number of exceptions)

But they've never really touched on my needs as a man. That's not something that was ever suggested or taken up. I think people don't sort of think about your gender, or who you're talking to, that you're an adult. I think I'm just seen as a disabled person. It's not about sexuality, it's not about...I'm not seen as a sexual person, or a person with feelings, or whatever.

They seem to be completely gender – it's not even gender neutral, because gender's not even in there. It's asexual, basically, approach to social care, in my experience. I think the actual impact of social care can be incredibly emasculating, if it is set up in such a way that it takes away your independence and your autonomy, that is incredibly emasculating. I think my sense of being a confident, successful man has only really come about to a real extent since I've moved out and had the 24 hour care package, which has allowed me to be completely independent.

# Headline findings

Participants offered accounts of their similarities and differences from stereotypes of 'ordinary' (usually non-disabled) men

I think I'm a regular bachelor....just a regular family guy..... Just the fulfilment, really. It feels like happiness, like it's a dream. That's all I ever want, really, to be normal. A normal person. If I wasn't disabled, I'd love to go to the shops, go shopping, get married, look after the kids, be a regular guy, really. Try to work and all that.

Well we don't look like the average man walking around the street.

Does that bother you at all?

Only in terms of when it comes to the ladies. I can't compete against the average man in terms of the way I look. Not because it makes me look funny, but obviously I'm not a completely normal shape to everybody else. So I think it's more about what the ladies think. Yeah. What do you think the ladies think?

I don't know. I feel like they're probably not looking for somebody like me. I mean I've had girlfriends before, but I've only had, like disabled as well. I don't have much confidence with the ones who aren't disabled, because I feel that the standards might be a bit different.

# Headline findings

## Constructions and perceptions of being a man which arguably challenge stereotypes in a positive way

- Maturity and self-awareness mattering more than muscles  
A man isn't defined by his muscles, he's defined by how mature he is.
- Understanding that being a man with DMD necessitates care and support  
Because I'm disabled and I'm a man, I think you're more of a man if you accept that you need help. That's strength. It's not a weakness. I need to accept care. I think that men use tools and stuff. Carers are like the tools to help you in your life, really.
- Achieving states of independence (physical or mental) which may not necessarily involve moving out of the family home
- Emotional strength and maturity developed by facing some of the trials and challenges associated with living with DMD.

# Headline findings

## Sex and intimate relationships

- Good experiences
- Needs and barriers
- Role of staff

I: So I wanted to ask, what about having sex, is that something you want?

A: I haven't tried yet. I would like it, actually.

I: Have you ever talked to anyone about that, like care staff, how you might do that?

A: I do speak with [name], who works here. She's a nice person, actually.

I: Do you? What kind of things do you talk about?

A: Sometimes my social worker comes to visit, we have a big chat and that.

I: Oh right. And do they ask you about that, relationships and sex and that kind of thing?

A: Yeah. I just want to have a good relationship. If I want to have sex with a woman, it's the protection bit I'd need to get a lady to do for me, I wouldn't be able to do it.

I: But it's good you've got someone you can talk to about that kind of stuff.

A: Yeah. When I used to live at home, I used to look on these porn sites, because I want to be a disabled porn star, I do, myself.

I: Oh really? Awesome. Cool, why do you want to be...?

A: Yeah, just show all the boys with Duchenne out there to see what the experience is like and that.

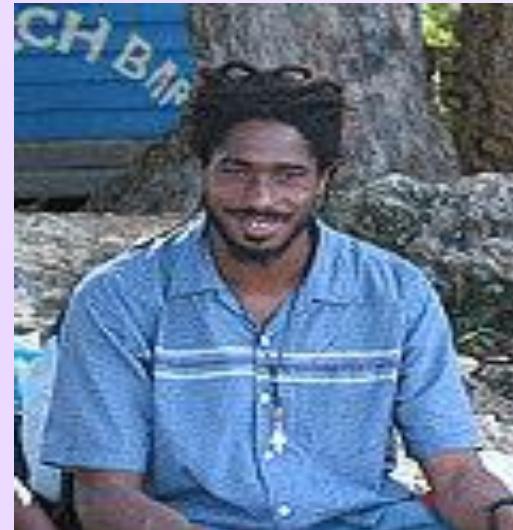
# Headline findings

Intersection of disability and gender often overlooked whilst health/disability identity is foregrounded.

- Who are the social care actors?
- Pressure to move onto continuing health care
- Focus on risk and fragility
- Emasculating interactions
- Not being given cues that it's good to talk (when it happens it's very positive).

# Next steps

- Short film
- CA analysis
- Other outputs



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This presentation reports on independent research funded by the NIHR School for Social Care Research. The views expressed in this presentation are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health/NIHR.