

We're trying to make sure that a longer life is not an emasculated one for these young men

Boys with Duchenne muscular dystrophy (DMD) typically died as teenagers, but now live much longer. Our unique research asks how social care, through greater gender sensitivity, can make more of their unplanned-for longevity.

A recent study of service provision for young men with the degenerative condition, Duchenne muscular dystrophy (DMD), raised a worrying issue. 'We realised that there were quite a lot of examples of these men feeling emasculated by the support they were getting', explains David Abbott from Bristol University's School for Policy Studies.

'For example, because quite a lot of personal assistants are young women, some young men found themselves in shopping malls, waiting outside Claire's (the fashion accessory shop), while their assistant had a browse through. Or they were dependent on their mothers for personal or intimate care at an age when that does not really work for them. They didn't have real conversations with a social worker about sex or sexuality or about the deterioration of their bodily functions or even about how they might have sex, with themselves or anyone else.

'Most of the young men wanted to have, but were not having, a sexual relationship and some commented that they would need physical support to have sex and they had no idea how that would work. No-one said they had access to sex workers. I could see that the men really

wanted a relationship – they weren't looking for casual sex. I observed a loss of hand function in young men with DMD. How, I wondered do you masturbate? I didn't ask.'

It's these types of issues, thrown up by his earlier work, which prompted David Abbott to set up this new research project, focussed on gender. The team includes a researcher with DMD, Jon Hastie, who recently made an award winning film about his life with Duchenne.

'I observed a loss of hand function in young men with DMD. How, I wondered do you masturbate? I didn't ask. But we must follow up these issues. "Why do you keep talking about adults?" one young man asked me. "We're all men".'

David Abbott, researcher

Mr Abbott accepts that earlier research neglected to properly examine gender at all. 'I realised that I had been treating this group as rather genderless. "Why do you keep talking about adults?" one young man asked me. "We're all men".'



Sex is not the only issue. 'In our society, it is very difficult for these young men to achieve the classic markers of masculinity – driving, sex, work, physical and psychological separation from parents. We are interested in whether members of this group find other ways to successfully conceptualise being a man. Can they develop or exert masculinity in other ways?'

The team has found that through mastering certain aspects of technology in relatively solitary ways, these young men do express elements of conventional masculinity. 'A lot are IT skilled or computer game orientated and the element of mastery is very important. One guy was writing a novel. He was isolated, but his identity as a writer was important

to him. Sadly, it was not always valued by those around him because it did not fit their model of "work".'

The research aims to find out more about these young men's interactions with social care professionals and how their gender is supported. The team will consider whether the predominantly female world of social care professionals and paid care workers is an issue. In Mr Abbott's previous study most men said that their ideal personal assistant would be male, about their age or a bit older, with similar interests.

The study aims to develop thinking about men living with long term conditions. Society tends to regard men living with disability as less than real men, particularly today as body shape and image are more important than before. It is important that social care does not reinforce this diminishing of social status.

'Maybe, we need to think about the gender mix of the workforce,' says Mr Abbott. 'Or may be pay attention in paper work to include questions about sex and relationships. How should we talk to them about giving lots of steroids that enhance mobility but delay growth and puberty? To my knowledge, no-one discusses the trade off between better health and a very delayed physical transition to manhood, an emasculation.'

Gender has not featured large in academic research about disability with the focus being on broad equality goals and combating discrimination. 'The disability community might say that it has sometimes focussed on a collective goal, without enough emphasis on diversity within disability. We hope this research begins to set the balance right.'

Project: [Men living with long-term conditions: Exploring gender and improving social care](#)

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