

## Scoping social care priorities for young adults with neuromuscular conditions

### The starting point

Most research begins with a set of aims and objectives and usually some idea about design and methods. Thanks to funding from the NIHR School for Social Care Research, this project aims to add to an existing portfolio of projects that aim to do things a bit differently, by way of 'co-producing' from the very start.

According to Filipe, Renedo, and Marston (2017), 'co-production' can be understood as;

*"... an exploratory space and a generative process that leads to different, and sometimes unexpected, forms of knowledge, values, and social relations".*

To enable this generative process to have most impact on the development of a research study, it makes sense for co-production to occur at the earliest possible point in the research process. That means bringing together a group of individuals with shared experience *before* any research aims, objectives, or methods have been developed.

In the case of this project, our shared experience is of navigating social care and support as young adults with neuromuscular conditions. Neuromuscular conditions (NMCs) can be understood as a group of conditions that cause progressive weakness and loss of muscle mass. They can include conditions such as Duchenne Muscular Dystrophy, Spinal Muscular Atrophy, and Central Core Disease. You can find out more [here](#).

A recently published report by the House of Lords Adult Social Care Committee titled 'A gloriously ordinary life: spotlight on adult social care' describes how social care *"is poorly understood and often neglected by policy makers, the public and the media-and the impact this has had, in particular, on disabled adults..."*(House of Lords. Adult Social Care Committee, 2022). This statement is indeed reflective of our experiences, with evidence to suggest our experiences are more widely shared among other young adults with NMCs (Abbott & Carpenter, 2014; Abbott, Carpenter, & Bushby, 2012; Abbott, Jepson, & Hastie, 2016; Gibson, Young, Upshur, & McKeever, 2007).

It is our aim to provide an exploratory space to collectively generate and reimagine how social care and support should be experienced by young adults with NMCs. From this point, we aim to scope and identify priorities for research in social care. Moving forward to develop one of our identified priorities into a research study. Our aim is to submit a funding application in July 2023 that will form the basis of an NIHR Advanced Fellowship application (April call).

Why not follow us as we work collectively to build and develop a study we hope will work towards improving adult social care and support for young adults with neuromuscular conditions. Our aim is to post a new blog at least monthly, summarizing our current progress and steps as we move towards study development. Each blog will be posted on our webpage which can be found [here](#).

### References

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