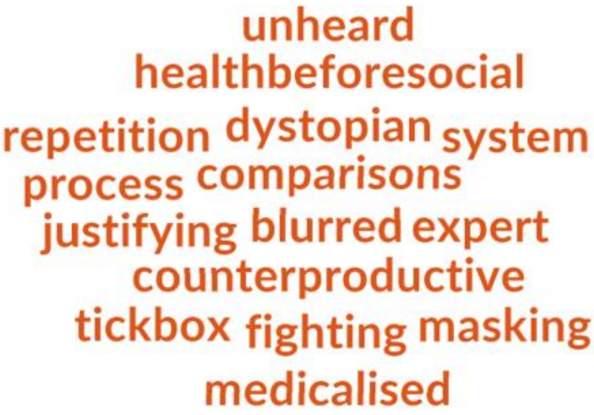
Unpicking the meaning of social care

As a group of relative strangers, it was important that we were able to anchor our ‘getting to know one another’ to an activity that also supported, and indeed laid the foundation for our priority setting work. Given our shared aim of co-producing a study based on an identified social care/support priority for young adults with neuromuscular conditions (NMCs), we felt it made sense to start by answering, ‘what do we understand the term social care to mean’.

Each of us have unique experiences and subsequent understandings of ‘social care’ and so we began by collectively sharing our experiences of social care and support. This exercise formed the basis of our first group meeting and led to us identifying the keywords highlighted in diagram 1.

Diagram 1: How do we currently experience the social care and support system?



These keywords reflect our collective experiences of social care. We then sought to develop a definition of social care, based on the keywords identified that reflect our experiences. Our first attempt led to the following definition;

> *‘Social care as a young adult with a neuromuscular condition means engaging with a blurred space that feels undistinguished from health services in its focus on preserving life as opposed to promoting living. Accessing social care requires a fighting mentality sustained by resilience, built from a requirement to repeatedly justify my needs, within a tick box system that requires me to be the expert of both my condition and the workings of the system’.*

To break the definition down, we first wanted to highlight how social care exists to us a blurred space. By ‘blurred’, we mean that it is hard to distinguish social care from the healthcare we receive. This is not always a negative, but often we feel the care we do receive exists to preserve life as opposed to promote our living. To give an example, for those of us who receive 24hr care packages, there existence is based on our health needs (in case for example we asphyxiate), as opposed to what equally matters, our social needs. Relatedly, it is the focus on health that we feel leads to a need to be both an expert of our own condition and indeed the workings of the system. Put bluntly, we feel that if we were to put the case for our care package based on its capacity to allow us to live relatively independently, our package would be refused. More broadly, the requirement to fight, justify, and be resilient reflect our experiences of engaging with social care services to date. When having our needs assessed or reassessed, the focus always seems to be about money, as opposed to ourselves as individuals. Likewise, there sometimes feels to be little room to express our own preferences and wishes, with interaction akin to a ‘tick box’ format. This makes these processes stressful, anxiety inducing, patronizing, and just generally makes us feel pretty rubbish.

Having drafted the first definition based on discussion during our first meeting, we went away to reflect on the definition and whether it needed to be edited/added to. After further discussion, we came up with the following updated definition of social care as experienced:

‘Social care as a young adult with a neuromuscular condition means engaging with a system that fails to adapt to our needs as young people transitioning from child to adult services. Engagement with adult services can feel patronizing on account of engaging with a system where I have to repeatedly justify my needs as a young adult. Initial engagement with social care services, such as in the form of a needs or health assessments can feel as if I am a number, with a need to reach a certain score to ‘qualify’ for care. Post-assessment, it feels like money and cost come before all else, including my needs. As a result, reviewal of my care package can be scary, stressful, and anxiety inducing, characterized by a continuous need to fight for my care, with the ongoing threat of my individual choices and needs being prohibited by a system that should be championing them’.

Absent from the first definition, was an acknowledgement of the pivotal process of transition to adult services, and the failures of this process that we have experienced. We also further emphasized the feeling of being a ‘number’ as opposed to an individual when it came to engaging with social care services. Likewise, we wanted the definition to encompass the different meet points with social care services as a young adult, from transition to adult services, to initial assessment of needs, to reviewal of needs and care packages.

Towards a brighter direction; how do we want to experience social care?

As a comparative exercise, we also discussed how we would wish to experience social care and support. Diagram 2 illustrates the various keywords that summarized our discussions with phrases such as ‘focused on what we can do’, ‘enabling’, ‘advocating’, and ‘individual’ particularly pertinent.

Diagram 2: How would we want to experience social care and support?

As with the first exercise, we then looked to build a definition of how social care and support should be, based on the identified key words. Our first attempt read as follows:

> *'Social care for young adults with neuromuscular conditions means an informed, approachable and coordinated system that advocates for and recognises individuality, and delivers care that supports daily independence in a manner that is meaningful to the individual'.*

Key components of the definition include an informed, approachable, and coordinated system that exists to support our everyday individual needs and aims. We then revised the definition, adding additional components we felt were missing. These included the importance of a system that responds and caters to our present needs and facilitates planning for the future. This creates a proactive system capable of delivering tailored care and support.

> *'Social care for young adults with neuromuscular conditions means a system that consistently delivers to the changing needs of the person as they go through young adulthood in a manner that is informed, approachable, and coordinated. This starts from an initial assessment of needs that accounts for the present needs of the individual, but also enables them to make long-term decisions about their care. Delivered care and support is therefore proactive as opposed to reactive, and goes beyond 'eat, sleep, repeat' to care experienced in a way that is meaningful to the individual. Reviewal of care is geared towards ensuring individual needs continue to be met with a care package that responds to such needs'.*

Summary thoughts

The fundamental aim of this exercise was to support us to begin to work collectively. Each of us are unique, with our perspectives and opinions of social care and support developed through our situated experiences. Completing this exercise provided the first step in bringing our perspectives together, sharing them, and laying the foundations both of our work to come and our connections to one another. As a by-product, we feel we have developed two definitions that are worthy of being shared outside of our group. We are not yet sure whether we will return to these definitions to further develop them as we continue on our co-production journey, or if they will exist as a reminder of our first outputs as a collective.

Having spent time thinking about what social care and support means to us, we now move onto scoping the experiences and evidence of others. More on that in our next blog.

N:B. These blog posts are currently drafted by George, and then shared and edited by the group collectively. Moving forward, we intend for each of us within the group to lead on the blog.