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Social Care and Young Adults with Neuromuscular Conditions Diagnosed in Childhood: A Co-Produced Scoping Review

RESEARCH

GEORGE PEAT
SUZANNE GLOVER
CATERINA RADU
STEVEN JONES
GRACE BINNEY
JAMES PARKIN
KIRSTY LIDDIARD
LORNA KATHERINE FRASER
DAVID ABBOTT

*Author affiliations can be found in the back matter of this article

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ABSTRACT

Context: The social care needs of young adults with neuromuscular conditions (NMCs) are poorly evidenced. To address the paucity in research, it is first necessary to consolidate current understanding of social care and its presence/absence in the lives of young adults with NMCs.

Objectives: To undertake a co-produced systematic scoping review to scope evidence on the presence of social care in the lives of young adults with NMCs. Specific objectives were to establish the extent of existing evidence, map key characteristics, identify evidence gaps and outline the most salient components of social care (e.g. housing) that exist in the evidence.

Methods: A systematic scoping review was co-produced alongside a group of five young adults with NMCs. Review methods followed published guidelines. Searches were conducted in relevant databases.

Findings: Findings from 25 studies were included representing 599 people with NMCs, 253 informal caregivers, 7 siblings and 11 professionals. The scope of available evidence exists across seven identified components. Namely, informal care, personal assistance, independence, interaction with the social care system, adaptations and equipment to support everyday living, opportunities to socialise and relationships and intimacy. Considerable variance in care quality and availability was identified.

Limitations: Despite a comprehensive literature search, only 25 studies were identified internationally, representative of the health-oriented nature of evidence on this population. Professional perspectives were also lacking.

Implications: Findings highlight where current evidence is situated and where gaps exist. As such, the review provides a foundation to direct vital research in this area.

CORRESPONDING AUTHOR:
George Peat
Northumbria University, UK; Member of the scoping social care priorities for young adults with NMCs group, University of York, UK
george.peat@northumbria.ac.uk

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BACKGROUND

The social care needs of young adults with neuromuscular conditions (NMCs) diagnosed in childhood are poorly understood (Abbott, Jepson and Hastie, 2016; All Party Parliamentary Group for Muscular Dystrophy, 2008; Glover *et al*., 2023). In part, this is because the group has been predominantly viewed through a healthcare lens (Birnkrant *et al*., 2018). Whilst important, an apparent consequence has been an under-recognition of the social support required to enable many young adults with NMCs to live meaningful and fulfilling lives (Abbott and Carpenter, 2009; Gibson *et al*., 2007). A shift in focus is therefore required to draw attention to *living with* a NMC, not least because of significant increases in life expectancy for young people with some NMCs, such as Duchenne muscular dystrophy (DMD), due to advancements in, among other areas, respiratory support (Birnkrant *et al*., 2018).

NMCs are defined as a group of individually rare conditions that affect muscle functioning (Carey *et al*., 2021). Studies suggest the prevalence of NMCs is rising due to advances in clinical management (Carey *et al*., 2021; Müller *et al*., 2021). For example, in England, a recent study found an increase in lifetime prevalence from 136 per 100,000 in 2000 to 224 per 100,000 by 2019. More specifically, the same study found an increase in the prevalence of muscular dystrophies, with an estimate of 29.5 per 100,000 in 2019 compared to 19.2 in 1994 (Carey *et al*., 2021). It is likely that the prevalence of NMCs will continue to rise in line with advancements in diagnostic methods (Thompson *et al*., 2020). There are many different types of NMCs, and symptom severity can vary significantly between individuals (Neuromuscular Disease Foundation, 2022).

Young adults with NMCs arguably have distinct needs as a group compared to young disabled people in general. For example, many must contend with consistent existential uncertainty and long periods of ill-health, including often undergoing major surgery throughout their lives (Abbott and Carpenter, 2014a; Abbott *et al*., 2017). The use of both invasive and non-invasive ventilation is also common as a treatment to aid respiratory function (Birnkrant *et al*., 2018). Similarly, as treatments and therapies continue to advance, it is likely horizons and perspectives on adulthood may continue to shift and adjust. Consequently, it is necessary to factor the unique positionality of this group when considering the provision and delivery of appropriate adult social care and support.

The social care support needs of young adults with NMCs can vary depending on factors such as specific condition and the severity of symptoms. For instance, due to the progressive nature of conditions, by the time a person living with DMD reaches adulthood, they are likely to require 24-h care and support for everyday tasks and activities. By contrast, adults with other NMCs such as spinal muscular atrophy type 3 may experience less severe symptoms and therefore require less support (Abbott, Jepson and Hastie, 2016; Ch'ng *et al*., 2022; Glover *et al*., 2023). Other intersections including gender, housing and family dynamics also influence and impact on the care needs of individuals (Abbott and Carpenter, 2009; Abbott, Jepson and Hastie, 2016; Glover *et al*., 2023). Tailoring and developing appropriate adult social care and support requires clear consideration and understanding of the specific needs and wishes of the individual.

In the UK, adult social care refers to the personal and practical care and support that people may need because of age, illness, cognition, disability or other circumstances to facilitate daily living. It also includes support for family members or other unpaid carers' (Glasby *et al*., 2023; NIHR School for Social Care Research, 2023). However, the practice and construct of social care appear less defined when applied to young adults with NMCs. Specifically, it remains unclear exactly what constitutes 'social care' in the lives of young adults with NMCs.

Key reports such as the Walton Report (2008) and the more recent UK Adult Social Care Committee Report (2022) have repeatedly highlighted a failure to acknowledge and subsequently deliver appropriate and tailored adult social care and support for this group. Consequently, improving the provision of social care and support to young adults with NMCs in the UK is paramount.

Young adults with NMCs have rarely been involved in research as co-researchers. Rather, in line with broader research practice, their role in research has largely been as 'participants' (Dreyer, Steffensen and Pedersen, 2010; Gibson *et al*., 2014; Yamaguchi, Sonoda and Suzuki, 2019). Establishing the extent and value of current evidence is reliant on the direct input of those who understand and can draw on unique experiences of the social care system. To align with the movement towards the consistent and meaningful integration of participatory approaches into research practice (e.g., Glover *et al*., 2023; Whitney-Mitchell and Evans, 2022), it is vital that young adults with NMCs are central to research enquiry.

To consolidate current understanding of social care and its presence/absence in the lives of young adults with NMCs, a scoping review was co-produced with a group of young adults who imparted their knowledge and expertise of social care from unique perspectives of living with varied NMCs.

METHODS

This systematic scoping review aimed to scope evidence on the presence of social care in the lives of young adults with NMCs. Objectives of the review were:

- Establish the extent of existing empirical evidence on social care and young adults with NMCs.
- Map the key characteristics of existing evidence including sample and methods.
- Identify gaps in current evidence.
- Scope how and in what ways social care is discussed across the evidence base.
- Identify the components of social care (e.g. housing) that exist in the evidence.

In line with review guidance (Levac, Colquhoun and O'Brien, 2010), a review protocol was co-produced with five young adults with NMCs, with input also from an information specialist from the University of York Health Sciences Department (copy available on request). Reporting follows the PRISMA-ScR checklist (Tricco *et al*., 2018).

THE RESEARCH TEAM

The review was co-produced alongside researchers (SJ, SG, CR, JP and GB) living with varying NMCs. Researchers met regularly as a collective over an 18-month period online to define and agree on the review's aim and objectives, refine the parameters of the review, undertake database searching, participate in title, abstract, and full text screening, and develop the outlined components of social care.

Each researcher contributed and helped to shape the review process and parameters by drawing on their unique, situated perspectives. Three researchers were female and two are male, residing in England (3), Northern Ireland (1) and Romania (1). One researcher lives with DMD, three with spinal muscular atrophy (Types 2 and 3) and one with central core disease. Variations in symptom severity meant each researcher imparted unique understandings of social care onto review stages.

Group members had varied experience with scoping reviews prior to participation. One researcher has a PhD, one is working towards a PhD, two have undergraduate degrees and one is college educated. GP worked with researchers to develop relevant review skills, working one-to-one with researchers where necessary. For example, in one meeting, papers outlining the review process (Arksey and O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010) were discussed. Relatedly, GP developed a guide to illustrate each stage of the review. Covidence software facilitated group engagement in the screening process (Veritas Health Innovation, 2023). Group input in each stage of the review process is outlined throughout.

SEARCH STRATEGY

Group members first discussed relevant key databases to search including MEDLINE, EMBASE, CINAHL, Web of Science, PsycInfo, ASSIA and the Social Care Institute for Excellence Database. GP undertook the searches on behalf of the team from inception to January 2024 (searches rerun May 24).

To supplement database searching, citation search, the searching of reference lists and a Google Scholar advanced search were undertaken. Exemplar articles were identified before the search and used to check the accuracy of searches. Searches were imported to EndNote (2022), duplicates were removed and uploaded to Covidence (Veritas Health Innovation, 2023) for screening.

The group then met to discuss relevant search concepts and search strings. Concepts were drawn from the review aim, namely, 'neuromuscular condition', 'adult' and 'social care'. Search strings for each concept were developed through a combination of methods. First, components of social care developed by the group were included. Additionally, the search strategies of previous reviews (e.g., Tucker *et al*., 2024) on the subject area were utilised (see supplementary material). Finalised search terms were then reviewed by the group before being applied across the outlined databases.

ELIGIBILITY

Eligibility criteria were decided among the group with studies selected according to this criterion (Table 1). Given the focus on identifying empirical evidence, opinion pieces and policy documents were excluded. Where the age range was not stated, the paper was discussed as a group based on its contribution to the aims and objectives of the review. In instances where the search identified a review, articles included in the review were assessed for relevance in line with the eligibility criteria (Table 1).

STUDY SELECTION

Initial searches identified 3227 references following the removal of duplicates. References were screened using the software Covidence (Veritas Health Innovation, 2023). Following the removal of duplicates, the group met to discuss the screening process. Where appropriate, GP provided additional training and guidance to group members to support their participation in the process. Group members then participated in title, abstract and full-text screening, drawing on the agreed eligibility criteria (Table 1). At least two group members/authors needed to agree on the decision of each paper. Any disagreements were resolved through group discussion. In line with the aims of the review and its scoping nature, quality appraisal was not undertaken.

DATA EXTRACTION AND SYNTHESIS

In preparation for data extraction and synthesis, the group met online to discuss the types of information that were important to extract from the included papers. This included the author(s), date published, country of origin, participant characteristics, period of data collection,

CRITERIA	INCLUSION	EXCLUSION
Publication type	▫ Peer reviewed journal papers ▫ Grey literature (e.g., charity reports)	▫ Poster abstracts ▫ Theses ▫ Commentaries or editorials
Type of article	▫ Empirical research	▫ Policy papers or opinion pieces ▫ Theoretical papers ▫ Reviews of empirical research
Location	▫ Data from any country	▫ None
Publication language	▫ English	▫ Languages other than English
Population group	▫ Young adults (50% sample between ages of 16 and 35) with NMCs diagnosed in childhood (e.g., DMD, SMA type 2, 3) ▫ Carers of young adults with NMCs ▫ Where papers included a mixed sample of physically disabled adults >40% had an NMC	▫ Health professional opinion pieces or editorials ▫ Adults with NMCs diagnosed in adulthood (e.g., amyotrophic lateral sclerosis)

Table 1 Eligibility criteria.

method of data collection, type of evidence and study aim. A shared document data extraction form was then created to facilitate group members in extracting the data.

Establishing how and in what ways 'social care' is discussed across the evidence base was a key objective of the paper. Utilising the definition of social care offered by the NIHR School for Social Care Research (2023) and drawing on the lived experiences and perspectives of the group, key 'components' of social care were developed prior to data synthesis. These included forms of care (informal care and personal assistance), ideal outcomes of social care (notions of independence and opportunities to socialise), interactions with what we called the 'system' (typically engagement with local authorities via social workers to obtain funding, formal care and equipment) and areas where social care felt particularly absent by the group such as in supporting relationships and intimacy. Areas such as education and employment, whilst important, were judged to fall outside of the remit of social care and were therefore not explored.

Summaries of evidence underpinning each component were then developed by drawing from data across the included papers.

RESULTS

IDENTIFICATION AND SELECTION OF STUDIES

Of the 3227 references identified (following removal of duplicates), a total of 3052 references were excluded during title and abstract screening, 175 full texts were reviewed, 148 references were removed at this stage, leading to the inclusion of 27 papers from 25 studies (Figure 1, PRISMA diagram).

CHARACTERISTICS OF INCLUDED STUDIES

Papers were published between 2005 and 2023 (mean: 2016). Where specified, data was collected between 1996 and 2022. Papers included samples from the following countries: England (11), Canada (6), Denmark (3), Japan (2), Scotland (1), Sweden (1), USA (1), Taiwan (1), Malaysia (1), Australia (1), Germany (1) and Netherlands (1). Three studies included a sample from more than one country (Table 3, supplementary material).

Most studies adopted a qualitative design (18) and predominantly used interview approaches to collect data. Other designs included mixed methods (4), cross-sectional survey design (3), a retrospective review of records (1), and a case series (1). No intervention studies were identified. One qualitative study used co-production methodology (1) with limited evidence of public involvement and engagement identified in other studies (Table 3, supplementary material).

CHARACTERISTICS OF PARTICIPANTS

Where stated, papers included samples of a total of 599 people with NMCs. Most papers, when stated, including a sample of young adults with DMD. Other NMCs represented included spinal muscular atrophy types 2/3, Becker's muscular dystrophy, congenital myopathies/muscular dystrophies, cerebral palsy, recessive limb-girdle muscular dystrophies, spina bifida and other unspecified neurological condition(s). Age of participants ranged from 14 to 54 years with most aged between 16 and 35 years. Most young adults were male reflective of study samples predominantly being young adults with DMD, although the perspectives of females were represented in studies with a sample of young adults with conditions such as spinal muscular atrophy.

In addition to young adults, the perspectives of 253 informal caregivers (predominantly parents or partners of people with NMCs), 7 siblings and 11 professionals (3 hospice workers and 8 healthcare professionals) were represented across included studies. No studies identified sought the perspective of social care professionals working with young adults with NMCs (Table 3, supplementary material).

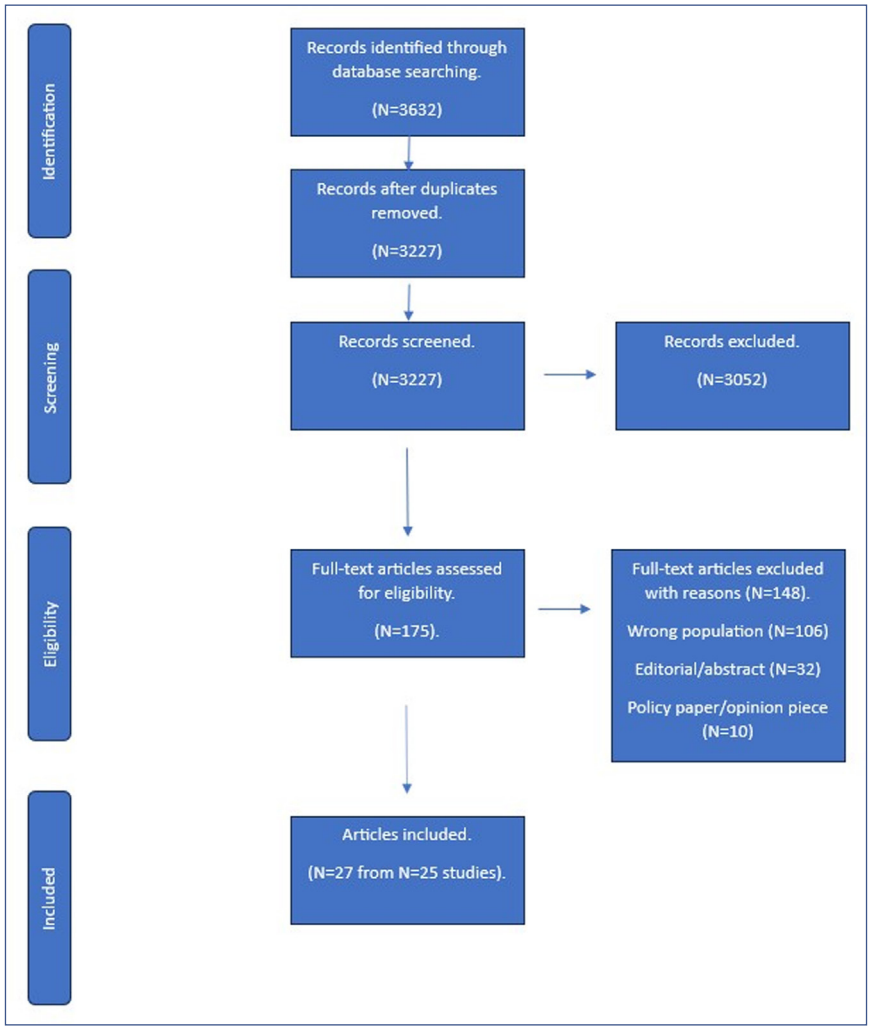

Figure 1 Preferred reporting items for systematic reviews and meta-analyses flowchart showing the inclusion of 27 articles (25 studies) from 3632 identified.

SOCIAL CARE COMPONENTS

Evidence pertaining to each of the seven social care components (derived prior to analysis) was identified across accepted papers. Informal care (18/27) and independence (19/27) were the most common components (Table 2).

COMPONENTS OF SOCIAL CARE

Informal care

Informal care is predominantly provided by relatives, majority by parents or partners of young adults with NMCs (Aho, Hultsjö and Hjelm, 2015; Aranda-Reneo *et al*., 2020; Ho *et al*., 2016; Parker *et al*., 2005; Yamaguchi, Sonoda and Suzuki, 2019). This type of care appeared to support 'basic activities of daily living' including maintaining hygiene, dressing and preparing meals (Aho, Hultsjö and Hjelm, 2015; Aranda-Reneo *et al*., 2020; Ho *et al*., 2016). We identified little evidence of informal care being used to support socialising. Reasons for drawing on informal care included concerns about privacy (Abbott and Carpenter, 2009; Wan *et al*., 2019), lack of assessment (Parker *et al*., 2005), low trust in external care or a belief that standards of care would not meet those offered by informal carers (Dreyer, Steffensen and Pedersen, 2010; MacLaren *et al*., 2019; Pangalila *et al*., 2012) and poor availability of external care (Pangalila *et al*., 2012; Wan *et al*., 2019). Evidence suggests informal carers largely value their role but face considerable physical and mental challenges, including sleep disturbance, injury, stress and anxiety (Abbott and Carpenter, 2009; Ch'ng *et al*., 2022; MacLaren *et al*., 2019; Pangalila *et al*., 2012; Yamaguchi, Sonoda and Suzuki, 2019). Both young adults and their carers have voiced concern about care delivery as carers age (Ch'ng *et al*., 2022; Ho *et al*., 2016; Pangalila *et al*., 2012; Powell and Carlton, 2023; Yamaguchi, Sonoda and Suzuki, 2019). While some studies described close relationships between informal carers (e.g. mothers) and their child, others reported conflict and difficult relationships (Abbott *et al*., 2019; MacLaren *et al*., 2019; Wan *et al*., 2019).

Personal assistance

Personal assistance referred to externally sourced care funded through processes such as direct payments (Disability Rights UK, 2022). Receiving external care was described in some studies as a 'battle'; typified by

PAPER	INFORMAL CARE*	PERSONAL ASSISTANCE	INDEPENDENCE	INTERACTION WITH THE SOCIAL CARE SYSTEM	ADAPTATIONS AND EQUIPMENT TO SUPPORT EVERYDAY LIVING**	OPPORTUNITIES TO SOCIALISE	RELATIONSHIPS AND INTIMACY
Powell and Carlton (2023)	✓	✓	✓		✓	✓	✓
Ch'ng *et al.* (2022)	✓		✓	✓			
Abrams, Abbott and Mistry (2020)				✓			
Parker *et al.* (2005)	✓	✓	✓	✓	✓		
Rahbek *et al.* (2005)		✓	✓		✓	✓	✓
Abbott *et al.* (2009)	✓	✓	✓	✓	✓	✓	✓
MD UK (2015)			✓	✓	✓		
Abbott *et al.* (2019)	✓	✓	✓	✓		✓	✓
Wan *et al.* (2019)	✓	✓		✓	✓	✓	
Carin Aho *et al.* (2016)		✓				✓	
Gibson *et al.* (2014)	✓		✓		✓		✓
Gibson *et al.* (2007)	✓	✓	✓		✓	✓	✓
Kirk *et al.* (2014)			✓	✓	✓		
Yamaguchi *et al.* (2013)	✓		✓				
Yamaguchi *et al.* (2019)	✓						
Ho *et al.* (2016)	✓	✓	✓		✓		
Dreyer *et al.* (2010)	✓	✓	✓			✓	✓
Abbott *et al.* (2016)		✓	✓	✓		✓	✓
Janish *et al.* (2020)	✓						
Rosario *et al.* (2022)				✓			
Hamdani *et al.* (2015)	✓	✓	✓			✓	✓
Hoskin *et al.* (2021)	✓	✓	✓			✓	✓
Abbott *et al.* (2014a,b)				✓			
Carin Aho *et al.* (2015)	✓	✓	✓	✓		✓	
MacLaren *et al.* (2019)	✓	✓	✓	✓	✓		
Pangalila *et al.* (2012)	✓						
Glover *et al.* (2023)			✓			✓	
TOTAL	18	15	19	13	11	13	10

Table 2 Components of adult social care identified in reviewed papers.

*Informal care: Care provided by family members or friends, as opposed to an external organisation. Paid or unpaid (van den Berg *et al.*, 2004).

**Adaptations and equipment to support everyday living: Refers to housing adaptations and equipment that supports everyday living and functionality. For example, hoists, toileting aids, adjustable beds, wheelchairs (powered/manual) and accessible vehicles.

a need to justify support (Abbott and Carpenter, 2009; Aho, Hultsjö and Hjelm, 2015; MacLaren *et al*., 2019). In other countries, most notably Denmark, funded personal assistance was described as 'the norm' (Dreyer, Steffensen and Pedersen, 2010; Hoskin, 2021; Rahbek *et al*., 2005). There was substantial variation in the quality of external care. For instance, some studies described 'round the clock' support (Abbott *et al*., 2019; Gibson *et al*., 2007; Rahbek *et al*., 2005) whilst others described inflexible care arrangements (Abbott and Carpenter, 2009; Aho, Hultsjö and Hjelm, 2016; MacLaren *et al*., 2019; Wan *et al*., 2019) and examples of being ridiculed, unpleasant behaviour or care tasks being poorly performed (Abbott, Jepson and Hastie, 2016; Abbott *et al*., 2019; MacLaren *et al*., 2019; Wan *et al*., 2019). These experiences impacted feelings of trust, understood as integral to good interpersonal dynamics between young adults and their personal assistants (MacLaren *et al*., 2019; Powell and Carlton, 2023). The recruitment, retention of staff and associated administrative tasks were described as challenging (Hoskin, 2021; MacLaren *et al*., 2019; Wan *et al*., 2019).

Independence

Independence was discussed, in some capacity, by several studies (e.g., Abbott and Carpenter, 2009; Abbott, Jepson and Hastie, 2016; Abbott *et al*., 2019; Ch'ng *et al*., 2022; Dreyer, Steffensen and Pedersen, 2010; Gibson *et al*., 2014; Glover *et al*., 2023; Hamdani, Mistry and Gibson, 2015; Ho *et al*., 2016; Hoskin, 2021; Powell and Carlton, 2023; Wan *et al*., 2019). The ability for young adults with NMCs to feel and express choice and control over their lives was core to feeling independent (Abbott, Jepson and Hastie, 2016; Abbott *et al*., 2019; Gibson *et al*., 2014; Glover *et al*., 2023; Hoskin, 2021; Powell and Carlton, 2023). Choice and control were experienced through being able to direct their care, engage in decision making about their care and live active lives (Abbott, Jepson and Hastie, 2016; Dreyer, Steffensen and Pedersen, 2010; Gibson *et al*., 2014; Glover *et al*., 2023; Powell and Carlton, 2023). Feeling independent was equated to being 'an adult' and fulfilling gendered identities (e.g., 'being a man'; Abbott *et al*., 2016; Abbott *et al*., 2019). Inflexible care arrangements, poor accessibility and inequitable provision of equipment (e.g., wheelchairs) could substantially hinder independence (Abbott and Carpenter, 2009; Ch'ng *et al*., 2022; Dreyer, Steffensen and Pedersen, 2010; Gibson *et al*., 2014; Powell and Carlton, 2023).

Living independently was most often described as living outside of the family home, for instance in private accommodation, supportive housing or long-term care facilities (Gibson *et al*., 2007; Hoskin, 2021; Janisch *et al*., 2020; Parker *et al*., 2005; Rahbek *et al*., 2005). For some, living outside of the family home increased feelings of choice, control and confidence (Abbott, Jepson and Hastie, 2016; Dreyer, Steffensen and Pedersen, 2010; Hoskin, 2021; Rahbek *et al*., 2005). Studies suggest many young adults with NMCs continue to live in the family home as they enter adulthood (Abbott and Carpenter, 2009; Abbott *et al*., 2019; Gibson *et al*., 2014; Glover *et al*., 2023; Hoskin, 2021; Parker *et al*., 2005). Concerns about the quality of external care, having the confidence and skills to direct care, the availability of housing and being unaware of the option of moving out were reasons for not leaving the family home (Gibson *et al*., 2014; Hamdani, Mistry and Gibson, 2015; Hoskin, 2021). Studies that interviewed young adults who remained in the family home, found that feeling independent could still be achieved as long as these young adults could express choice and control in their lives (Abbott, Jepson and Hastie, 2016; Glover *et al*., 2023).

Interaction with the social care system

'Systems' of social care varied across countries. In UK studies, interaction with local authorities to obtain and maintain care packages was commonly summarised as challenging due to unnecessarily bureaucratic processes that demanded considerable energy, time and resources from families (Abbott and Carpenter, 2009; Abrams, Abbott and Mistry, 2020). Obtaining support appeared to become more difficult when families transitioned to adult social care, a process described as fraught, stressful, and difficult, and exacerbated by the absence of or inconsistent support from a named social worker (Abbott and Carpenter, 2009; Del Rosario *et al*., 2022). Transition to adult social care was also reported to result in reduced support and provision (Abbott and Carpenter, 2009; Abbott and Carpenter, 2014b; Kirk and Fraser, 2014).

Challenges with transition to adult services and access to equitable adult social care (including funding) were also identified in international studies (e.g., Germany, Sweden, Australia and Japan; Aho *et al*., 2015; Janisch *et al*., 2020; Wan *et al*., 2019; Yamaguchi, Sonoda and Suzuki, 2019). Challenges accessing social (and health) support, funding or provision foregrounded young adults' 'disabled' identity, further amplified by the need to justify support by emphasising medical rather than social needs (e.g., risk of asphyxiation; Abbott *et al*., 2019; Aho, Hultsjö and Hjelm, 2015). These reported experiences jarred with the common narrative of wanting to *live* (Abbott and Carpenter, 2014b, Abrams, Abbott and Mistry, 2020). Of the included studies, only three studies with young Danish adults offered a counter-narrative, with seemingly higher standards of welfare and provision described (Dreyer, Steffensen and Pedersen, 2010; Hoskin, 2021; Rahbek *et al*., 2005).

Opportunities to socialise

Establishing and maintaining friendships through socialising and interaction was identified by studies as highly important to young adults with NMCs (Abbott and Carpenter, 2009; Aho, Hultsjö and Hjelm, 2015; Aho, Hultsjö & Hjelm, 2016; Glover *et al*., 2023; Hoskin, 2021;

Powell and Carlton, 2023; Wan *et al*., 2019). Yet, several studies report that young adults experience periods of isolation, loneliness and exclusion (Abbott and Carpenter, 2009; Ch'ng *et al*., 2022; Dreyer, Steffensen and Pedersen, 2010; Gibson *et al*., 2007; Powell and Carlton, 2023; Wan *et al*., 2019). Restrictive care packages, poor accessibility (e.g., buildings and transport), poor local amenities and stigmatising behaviours (e.g., bullying) were identified barriers to socialising (Abbott and Carpenter, 2009; Abbott, Jepson and Hastie, 2016; Dreyer, Steffensen and Pedersen, 2010; Glover *et al*., 2023; Powell and Carlton, 2023; Wan *et al*., 2019). Barriers such as poor accessibility and stigmatising behaviours existed in countries that otherwise described high standards of social welfare and support (Dreyer, Steffensen and Pedersen, 2010) Educational pathways (school, college and university) offered some opportunities to socialise, as did sporting activities such as club wheelchair football or hockey (Abbott and Carpenter, 2009; Dreyer, Steffensen and Pedersen, 2010; Gibson *et al*., 2014; Glover *et al*., 2023). Social lives outside of these spaces could be entirely dependent on family activities (Abbott and Carpenter, 2009; Abbott and Carpenter, 2014b).

Adaptations and equipment to support everyday living

Housing adaptations and equipment to support everyday living include appropriate hoists, toileting aids, adjustable beds and the conversion of accommodation (e.g., installation of wider corridors). Relatedly, wheelchairs (powered/manual) and adapted vehicles were commonly described to assist mobility (Abbott and Carpenter, 2009; Aho, Hultsjö and Hjelm, 2016; Ho *et al*., 2016; Muscular Dystrophy UK, 2015; Parker *et al*., 2005; Powell and Carlton, 2023; Wan *et al*., 2019). Young adults with NMCs relate the provision of equipment and adaptations to independence (Glover *et al*., 2023; Powell and Carlton, 2023). However, achieving these adaptations or equipment through identifying the necessary funding and support was a challenge identified across studies (Abbott and Carpenter, 2009; Ch'ng *et al*., 2022; Muscular Dystrophy UK, 2015; Parker *et al*., 2005; Wan *et al*., 2019). A total lack of or insufficient funding had a financial impact on families such as incurring financial debt as a result of having to self-fund adaptations or purchase equipment (Muscular Dystrophy UK, 2015).

Relationships and intimacy

The importance and value of relationships and intimacy to young adults with NMCs were identified across studies. However, studies suggested that barriers to these experiences exist. Notable barriers include the absence of the topic from discussions with social care professionals, insufficient guidance and understanding on how to have conversations about sex and intimacy with carers, concerns about privacy, poor accessibility hindering opportunities to meet others and negative perceptions of self-image (Abbott and Carpenter, 2009; Abbott, Jepson and Hastie, 2016; Abbott *et al*., 2019; Abrams, Abbott and Mistry, 2020; Dreyer, Steffensen and Pedersen, 2010; Gibson *et al*., 2014; Hoskin, 2021; Powell and Carlton, 2023; Rahbek *et al*., 2005).

DISCUSSION

Findings highlight considerable variance in the quality and availability of social care for young adults with NMCs. Evidence was predominantly qualitative and collected in the UK, although evidence was identified from a range of countries (n = 12 in total). Of the 599 young adults across identified studies, the majority lived with DMD. A total of 253 informal caregiver perspectives were also identified. The perspective of social care professionals or specialist roles (e.g., neuromuscular care advisors) was limited.

The United Nations Convention on the Rights of People with Disabilities outlines that 'disabled people should have the right to choose how to live their own lives and freedom to make their own choices' (United Nations Human Rights Office of the Commissioner, 2006). A key finding of studies included in this review was that young adults with NMCs attribute choice and control as core to feeling independent (Abbott, Jepson and Hastie, 2016; Abbott *et al*., 2019; Gibson *et al*., 2014; Glover *et al*., 2023; Hoskin, 2021; Powell and Carlton, 2023). Yet, this review identified minimal evidence of this reported in practice. Rather, many young adults with NMCs internationally appear to be restrained by social care that rarely extends beyond covering 'the basic activities of daily living' and whereby access to support in general is depictive of a 'battle'. Enacting 'choice and control' therefore appears to be restricted by social care systems working against rather than alongside young adults with NMCs.

The UK 2014 Care Act in many ways reflects the identified wishes of young adults with NMCs to, for instance, express choice and control in their everyday lives. For example, Section One of the Act states that the individual 'is in control' of care provided (Clements, 2024). However, there is consensus that the act has been poorly implemented in practice, resulting in minimal change for disabled adults and their carers (House of Lords. Adult Social Care Committee, 2022). Retrieved UK studies support this consensus in identifying the system barriers young adults with NMCs often face in receiving tailored social care and support. Despite aspirations for collaboration and co-production between users of services and social workers (Symonds *et al*., 2018; Whittington, 2016), this review identified that points in which professionals and young adults and their carers intersect (e.g., needs assessment and care package review), were typified by a requirement to 'battle'.

This review identified little evidence to suggest how relational dynamics between young adults with NMCs and social care professionals may be transformed to enact rather than hinder choice and control. Notably, the review identified that what is known about social care for young adults with NMCs is largely derived from studies on a particular component of social care, discussed from the perspective of young adults themselves and their informal carers. There is a distinct lack of research *with* social care professionals and allied roles (e.g. neuromuscular advisors). Consequently, we know little of the social care professional roles in supporting this group and the organisational challenges they may face in offering true choice and control to young adults with NMCs. For example, broader evidence suggests the advocated 'person-centred' approach to processes such as needs assessments can be constrained by restrictive statutory frameworks (Symonds *et al.*, 2018). Given the acknowledged positionality of professionals as 'gatekeepers of resources' (Symonds *et al.*, 2018), it is vital that future research intersects the perspectives of key professionals with those of young adults and their carers to explore social care holistically to determine the pathways to practical collaborative engagement.

What is clear is that differences in social care provision and experiences of accessing support exist. In particular, this review identified that in countries (e.g. Denmark) that historically have purveyed ideologies of social democracy and 'progressive models of citizenship', more equitable social care support for young adults with NMCs was identified (Hoskin, 2021). More up-to-date research is required to ascertain whether, given socio-political changes in these countries, (Baeten, Berg and Hansen, 2015; Hoskin, 2021) such differences in provision and social support remain. Furthermore, research is needed to understand why apparent differences in provision exist across regions and authorities. For example, this review identified no evidence on why variations in funding pathways exist (e.g. NHS Continuing Healthcare versus Local Authority funding). Neither did we identify UK studies that explored variation in social care practice across local authorities. Consequently, our understanding of why some young adults with NMCs appear to have comprehensive social care packages whilst others must fight and battle for substandard report remains limited.

The review further identified that despite being focussed on social care, included studies largely depicted social care as occurring in a medical paradigm, with care justified in response to medical concerns (e.g. risk of asphyxiation), as opposed to support living with a NMC (e.g. flexible care arrangements, equitable access to transport and equipment). The consequence, it appears, of a medical focus on social care, is that conversations that young adults with NMCs want to have with social care professionals are largely absent. For example, across identified studies, the review found little evidence of conversations to support engaging in socialising or relationships and intimacy.

A recent systematic review of 48 international studies on inaccessible urban public spaces highlights the substantial number of inaccessible elements disabled adults encounter when attempting to interact with public spaces. These include inaccessible pathways, transport infrastructure and buildings (e.g. narrow corridors and restrooms, inaccessible entrance features and improper service surfaces; Kapsalis *et al.*, 2024). Anecdotally, published works including 'when the world isn't designed for our bodies' (Waldman, 2020) depict the everyday ableism encountered by disabled adults. Ableism can be understood to mean a system that 'normatively privileges able-bodiedness' and in doing so discriminates and prejudices disabled people (Goodley, 2014).

Identified accessibility barriers were commonplace in the findings of the included studies. Faced with an ableist landscape, it is vital that young adults with NMCs have access to appropriate social care and support to enable them to navigate this world. Yet, this review identified restrictive care packages and the inequitable provision of equipment as widespread. Consequently, 'social care' mostly compounds rather than eases accessibility challenges, hampering opportunities to socialise, form relationships and develop a sense of independence.

Gaps in methodology and methods were identified. Despite growing recognition of the value of participatory approaches (e.g. co-production), evidence of such approaches was limited. Encouragingly, the most recent study identified was co-produced alongside young people with DMD, and undertaken by a user-led organisation (Glover *et al.*, 2023). Future research must continue to develop the participatory agenda to ensure research remains as close to and directly informed by young adults with NMCs. Identified papers were predominantly exploratory. Whilst the value of these studies is evident, so too is the requirement to further the agenda towards research that actively seeks solutions to the social care challenges identified. The opportunity for co-designed intervention research is therefore clear.

STRENGTHS AND LIMITATIONS

To the authors' best knowledge, this is the first co-produced systematic scoping review to identify and collate evidence on the role and presence (or lack) of social care in the lives of young adults with NMCs diagnosed in childhood. The engagement of co-researchers at each stage of the review led to key insights that helped shape the parameters of the review and develop the components outlined (Table 2). The intersection of review findings and co-researcher experiences aided the identifying of gaps in the evidence base. To be explicit, the involvement of young adults with NMCs as co-

researchers was integral to rooting the review scope, strategy, synthesis and discussion in the lived realities of the population of focus. A further strength of the review was the inclusion of international studies. Whilst variability in the understanding and application of social care internationally must be acknowledged, insights into how socio-political differences influence provision and support for young adults with NMCs were identified.

Despite a comprehensive search of the literature, including searches across health and social care databases, Google Scholar searches and the reviewing of reference lists, only 27 papers from 25 studies were identified internationally. This relative paucity in evidence is possibly depictive of the dominant health narrative associated with empirical evidence on young adults with NMCs. A further limitation was the lack of professional perspectives. It is vital that future research seeks to bring together professionals and young adults with NMCs and their carers to identify solutions to the challenges identified by this review.

IMPLICATIONS FOR POLICY

The Walton Report into access to specialist neuromuscular care in the UK, published in 2008 recommended 'a systematic review of social care support for people living with a neuromuscular condition' be undertaken by September 2010 (All Party Parliamentary Group for Muscular Dystrophy, 2008). No such review was identified in our searches. Therefore, it is unclear what evidence on social care published guidance on standards of care for NMCs such as DMD is based on. More so, such guidelines do not appear to feature the perspectives of social care professionals (Quinlivan *et al.*, 2021). This review outlines the key components where current evidence is situated and gaps in understanding and approaches. As a result, the review provides the necessary foundations to direct much-needed research into social care for young adults with NMCs.

GROUP REFLECTIONS

In participating in this review, members of the research team have sought to utilise and apply their own experiences of social care to define the review parameters and synthesise the evidence. Below, two researchers reflect on their engagement in the process.

> It's empowering to share a vision of illuminating and upturning social care in the context of neuromuscular conditions with both researchers identifying as disabled and non-disabled. As a young adult with a neuromuscular condition, medical needs have always been placed in foreground of (my/our) planning and decision-making. However, a life without opportunities to set personal goals and explore the freedoms of adult life, isn't living: it's just surviving. Thus, this process has been empowering as a result of the opportunity to explore such intimate and personal parts of life often downplayed throughout (our/my) life.

> My reflections are that it has been a rewarding and eye-opening experience. As someone with a disability you are very much told by the state that you need to follow the systems and processes already in place and rarely get the chance to challenge these. If you challenge them, you decrease your chances even further of receiving the support needed. This study so far has explored this in greater detail, looking at the person as a whole instead of solely their specific needs due to their disabilities.

CONCLUSION

Evidence from 25 international studies largely supports commissioned reports asserting that the quality and availability of social care for young adults with NMCs is considerably lacking. Addressing identified challenges is reliant on participatory research that moves the agenda beyond descriptively outlining the problem, to co-producing solutions through the meaningful involvement of all relevant stakeholders.

DATA ACCESSIBILITY STATEMENT

Data supporting this study are included within the article and/or supporting materials.

ADDITIONAL FILE

The additional file for this article can be found as follows:

- **Supplementary Material.** Search strategy (MEDLINE) and Table 3. DOI: https://doi.org/10.31389/jltc.350.s1

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

Peat, Glover, Jones, Radu, Parkin and Binney developed the review aim, objectives and social care components that supported data extraction and synthesis. Peat undertook the electronic searches. Peat, Glover, Jones, Radu, Parkin and Binney undertook article screening and data extraction, supported principally by Fraser. Peat drafted the manuscript with regular input from all authors. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

AUTHOR AFFILIATIONS

George Peat orcid.org/0000-0002-0293-2456
Northumbria University, UK; Member of the scoping social care priorities for young adults with NMCs group, University of York, UK

Suzanne Glover orcid.org/0009-0005-3705-4955
Pathfinders Neuromuscular Alliance, UK; Member of the scoping social care priorities for young adults with NMCs group, University of York, UK

Caterina Radu orcid.org/0009-0001-6386-8857
University of Strathclyde, UK; Member of the scoping social care priorities for young adults with NMCs group, University of York, UK

Steven Jones
Member of the scoping social care priorities for young adults with NMCs group, University of York, UK

Grace Binney
Member of the scoping social care priorities for young adults with NMCs group, University of York, UK

James Parkin
Member of the scoping social care priorities for young adults with NMCs group, University of York, UK

Kirsty Liddiard orcid.org/0000-0002-1220-3740
University of Sheffield, UK

Lorna Katherine Fraser orcid.org/0000-0002-1360-4191
Kings College London, UK

David Abbott orcid.org/0000-0002-3447-5368
University of Bristol, UK

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