National Institute for Health and Care Excellence

Draft for consultation

Rehabilitation for chronic neurological disorders including acquired brain injury

[K] Evidence reviews for access to support for education, employment and social participation

NICE guideline <number>

Evidence reviews underpinning recommendations 1.3.7, 1.9.9 to 1.9.12, 1.10.5 to 1.10.6 , 1.13.2, 1.13.6, 1.20.8, 1.22.8, 1.23.1 to 1.23.6, 1.24.1 to 1.24.9, 1.25.1 to 1.25.7, 1.26.1 to 1.26.3, and 1.27.1 to 1.27.11 in the NICE guideline

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This evidence review was developed by NICE

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Access to support for education, employment and social participation

Review question

Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

Introduction

Participating in education, employment, and social activities can be very challenging for people with chronic neurological diseases. Many of these people have also reported that finding the support to make this easier can be frustrating and can feel just as challenging. Identifying evidence on lived experience within these support services is one of the first steps in improving access to them.

The aim of this qualitative review was to determine what works well and what makes it difficult to access support for education, employment, and social participation for people with chronic neurological diseases.

Summary of the protocol

See Table 1 for a summary of the Population and Phenomenon of interest characteristics for this review.

Table 1: Summary of the protocol

Population	• Adults and children with rehabilitation needs due to the following chronic neurological disorders: ○ Acquired brain injury ○ Acquired spinal cord injury ○ Acquired peripheral nerve disorders ○ Progressive neurological diseases ○ Functional neurological disorders • Family and carers of people with chronic neurological disorders. • Health and social care practitioners who work with people with chronic neurological disorders. • Other professionals involved in supporting education or employment of people with chronic neurological disorders
Phenomenon of interest	• **Acceptability.** Data may relate to opinions about how access is affected by the way in which support is provided, including, for example, methods of provision, timeliness of support, and practicality of options for people using services. • **Availability.** Data may relate to people's experiences of the availability of support, including, for example, local rehabilitation resources, specialist neurological services. Also, about opening times, appointment systems and eligibility criteria. • **Accessibility.** Data may relate to the accessibility of clubs and societies (for example, after-school activities or sports teams). • **Integration (including communication).** Data may relate to how integration and communication between rehabilitation services and education, employment and community or leisure services affects access to support.

	• **Equalities considerations.** Data may relate to the extent to which support services are perceived to address equalities considerations, including, for example, support for people whose first language is not English, cultural sensitivity or age appropriateness. • **Provision of information.** Data may relate to the availability of information about how chronic neurological disorders may affect education/employment/social participation, the support available to them, or legal support requirements. • **Personalisation of rehabilitation goals.** Data may relate to people's views about whether accessing support enables the fulfilment of their own personalised goals for a return to employment, education, or broader social participation. • **Sustainability.** Data may relate to how people with relapsing-remitting chronic neurological disorders can access and re-access support services. • **Transition.** Data may relate to ease of access to support for people with chronic neurological disorders when changing jobs or transitioning between educational settings.

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document (supplementary document 1). The review protocol states that if insufficient UK data were available for the purposes of decision making about children and young people, then evidence from Australia, New Zealand and Canada would be considered. On discussing the results of the review, the committee agreed this was not the case so only UK evidence was considered for children and young people and for adults.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

Qualitative evidence

Included studies

Twenty-five studies were included for this review. Thirteen studies were general qualitative inquiries (Abbott 2014, Abbott 2016, Barrett 2022, Barrett 2023, Bennett 2023, Dunford 2020, Dyer 2014, Gibbs 2022, Hoskin 2021, Jones 2019, Kelly 2023, Salas 2021, Tresman 2016); 6 studies were phenomenological (Conneeley 2013, De Dios Perez 2022, Freeman 2020, Hooson 2013, Taylor 2011, Thrussell 2018); 4 studies were general qualitative inquiries within a mixed method study (De Dios Perez 2023, Jellie 2014, Learmonth 2013, Simpson 2020); 1 study was a case study (Jarvis 2022); and 1 study was grounded theory (Mullin 2018).

The included studies are summarised in Table 2.

Twenty-four studies were conducted in the UK (Abbott 2014, Abbott 2016, Barrett 2022, Barrett 2023, Bennett 2023, Conneeley 2013, De Dios Perez 2022, De Dios Perez 2023, Dunford 2020, Dyer 2014, Freeman 2020, Gibbs 2022, Hooson 2013, Jarvis 2022, Jellie 2014, Jones 2019, Kelly 2023, Learmonth 2013, Mullin 2018, Salas 2021, Simpson 2020, Taylor 2011, Thrussell 2018, Tresman 2016) and 1 study was conducted with participants from the UK and Denmark (Hoskin 2021).

Twenty-two studies included adults with chronic neurological disorders (Abbott 2014 [defined as people aged 15 years and above], Abbott 2016, Barrett 2022, Barrett 2023, Conneeley 2013, De Dios Perez 2022, De Dios Perez 2023, Dyer 2014, Freeman 2020, Gibbs 2022, Hooson 2013, Hoskin 2021 [defined as people aged 14 years and above], Jarvis 2022, Jellie 2014, Jones 2019, Kelly 2023, Learmonth 2013, Mullin 2018, Salas 2021, Simpson 2020, Taylor 2011, Thrussell 2018) and 3 studies included a paediatric population with chronic neurological disorders (Bennett 2023, Dunford 2020, Tresman 2016).

Thirteen studies investigated access to education, employment, and social support in people with progressive neurological disease (Abbott 2014, Abbott 2016, De Dios Perez 2022, De Dios Perez 2023, Freeman 2020, Hoskin 2021, Jarvis 2022, Jellie 2014, Jones 2019, Learmonth 2013, Mullin 2018, Simpson 2020, Taylor 2011); 9 studies included people with acquired brain injury (Bennett 2023, Conneeley 2013, Dunford 2020, Dyer 2014, Gibbs 2022, Hooson 2013, Kelly 2023, Salas 2021, Tresman 2016); and 3 studies included people with acquired spinal cord injury (Barrett 2022, Barrett 2023, Thrussell 2018).

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix J.

Summary of included studies

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies

Study	Participants	Methods	Themes applied after thematic synthesis
Abbott 2014 General qualitative inquiry UK **Aim** To explore the experiences of young men with Duchenne muscular dystrophy and their families when transitioning to adulthood (including from children's to adults' services and from education to employment).	N=95 young men with Duchenne muscular dystrophy plus parents and siblings CND category: Progressive neurological disease **Young men with Duchenne muscular dystrophy, n=37** Age in years [Mean (SD)]: 19.6 (SD not reported), age range 15-33 Sex (M/F): n=37/n=0 **Parents and siblings of young men with Duchenne muscular dystrophy, n=58** Age of people with chronic neurological	**Data collection:** Semi-structured interviews **Analysis:** Thematic content analysis	• Access to support for employment ○ Availability - Services to find employment ○ Accessibility - Bias and assumptions ○ Provision of information - Employment options • Access to support for social participation ○ Availability - Staff and resources ○ Provision of information - Information about local social activities

Study	Participants	Methods	Themes applied after thematic synthesis
	disorders in years [Mean (SD)]: As above Sex of people with chronic neurological disorders (M/F): As above		
Abbott 2016 General qualitative inquiry UK **Aim** To explore the experiences of young men with Duchenne muscular dystrophy with the delivery of social care and its impact on male identity.	N=20 young men with Duchenne muscular dystrophy CND category: Progressive neurological disease. Age in years [Mean (SD)]: Not reported, age range 21-33 Sex (M/F): n=20/n=0	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Accessibility - Discussions on intimacy and sexual well-being - Travel concerns and physical barriers ○ Integrating sexual rehabilitation
Barrett 2022 General qualitative inquiry UK **Aim** To explore healthcare professional’s experiences and views on the barriers and facilitators to accessing support for sexual functioning and well-being after spinal cord injury.	N=16 healthcare professionals working with people with spinal cord injury Chronical neurological disorder category: Acquired spinal cord injury Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Accessibility - Discussions on intimacy and sexual well-being ○ Integrating sexual rehabilitation ○ Provision of information - Information for sexual rehabilitation
Barrett 2023 General qualitative injury UK **Aim** To explore the views of people with spinal cord injury on psychosocial barriers and facilitators to	N=20 adults with spinal cord injury CND category: Acquired spinal cord injury Age in years [Mean (SD)]: 49.95 (13.42) Sex (M/F): n=15/n=5	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Acceptability - Attitudes of others - Support in group environments ○ Availability - Inpatient and outpatient sexual rehabilitation ○ Accessibility

Study	Participants	Methods	Themes applied after thematic synthesis
sexual functioning and wellbeing after injury.			- Discussions on intimacy and sexual well-being ○ Provision of information - Information for sexual rehabilitation
Bennett 2023 General qualitative inquiry UK **Aim** To explore the experiences of parents and carers of children with acquired brain injury during return to education, to identify barriers and facilitators to the process from their perspective and highlight key points for educational professionals to implement in their practices.	N=31 parents and carers of children and young people with acquired brain injury CND category: Acquired brain injury Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported, age range 5-18 Sex of children and young people with chronic neurological disorders (M/F): n=19/n=12	**Data collection:** Quantitative survey with free-text questions **Analysis:** Thematic analysis of free-text questions	• Access to support for education ○ Acceptability - Readiness of schools to engage - Timeliness of support ○ Integration (including communication) - Collaboration between healthcare and education - Communication from education to rehabilitation professionals - Communication from rehabilitation to education professionals ○ Transition ○ Advocacy - Healthcare professionals as advocates - Parents or carers as advocates
Conneeley 2013 Phenomenological UK **Aim** To explore the vocational goals and ambitions of people with traumatic brain injury after discharge from a neurological inpatient setting.	N=36 adults with traumatic brain injury plus family members CND category: Acquired brain injury **Adults with traumatic brain injury, n=18** Age in years [Mean (SD)]: Not reported, age range 17-60 Sex (M/F): n=13/n=5	**Data collection:** Semi-structured interviews, written notes, observation and prolonged engagement **Analysis:** Thematic analysis	• Access to support for employment ○ Personalisation of rehabilitation goals - Experimentation and feedback - Setting rehabilitation goals

Study	Participants	Methods	Themes applied after thematic synthesis
	Family members of adults with traumatic brain injury, n=18 Age of people with chronic neurological disorders in years [Mean (SD)]: As above Sex of people with chronic neurological disorders (M/F): As above Note: Study states '… members of the rehabilitation team were also recruited' (page 9) but no further details reported.		
De Dios Perez 2022 Phenomenological UK **Aim** To explore the experiences of people with multiple sclerosis with remaining in employment and accessing vocational rehabilitation, to identify barriers and facilitators for this support.	N=20 adults with multiple sclerosis plus healthcare professionals and employers CND category: Progressive neurological disease **Adults with multiple sclerosis, n=10** Age in years [Mean (SD)]: 47.5 (7.74) Sex (M/F): n=2/n=8 **Healthcare professionals working with people with multiple sclerosis, n=6** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data collection:** Semi-structured interviews **Analysis:** Thematic framework analysis	• Access to support for employment: Acceptability: Early provision of vocational rehabilitation ○ Acceptability - Flexible support - Involving employers in rehabilitation ○ Accessibility - Line managers as gatekeepers - Referral from other specialties ○ Provision of information - Information for employers

Study	Participants	Methods	Themes applied after thematic synthesis
	Employers of people with multiple sclerosis, n=4 Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported		
De Dios Perez 2023 General qualitative inquiry (within mixed-methods study) UK **Aim** To explore the feasibility and acceptability of a vocational rehabilitation intervention specifically designed for people with multiple sclerosis.	N=22 adults with multiple sclerosis plus healthcare professionals and employers CND category: Progressive neurological disease **Adults with multiple sclerosis, n=15** Age in years [Mean (SD)]: 46.13 (9.58) Sex (M/F): n=3/n=12 **Healthcare professionals working with people with multiple sclerosis, n=4** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported **Employers of people with multiple sclerosis, n=3** Age of people with chronic neurological disorders in years: Not reported	**Data collection:** Semi-structured interviews **Analysis:** Thematic framework analysis	• Access to support for employment ○ Acceptability - Involving employers in rehabilitation - Knowledge of healthcare professionals - Length of rehabilitation intervention ○ Integration (including communication) ○ Provision of information - Information for employers ○ Personalisation of rehabilitation goals - Workplace assessments

Study	Participants	Methods	Themes applied after thematic synthesis
	Sex of people with chronic neurological disorders: Not reported		
Dunford 2020 General qualitative inquiry UK **Aim** To explore the information needs (including content and format) of children and young people with acquired brain injury throughout their childhood.	N=6 children and young people with acquired brain injury CND disorder category: Acquired brain injury Age in years [Mean (SD)]*: Not reported, age range 9-17 Sex (M/F)*: n=1/n=4 *Characteristics only reported for n=5 participants.	**Data collection:** Email correspondence, semi-structured interviews, and focus groups. **Analysis:** Thematic analysis.	• Access to support for education ○ Provision of information ○ Sustainability - Repetition of information ○ Advocacy - Healthcare professionals as advocates
Dyer 2014 General qualitative inquiry UK **Aim** To explore healthcare professionals' views and experiences of sexuality-related discussions with people with traumatic brain injury.	N=24 healthcare professionals working with people with traumatic brain injury CND category: Acquired brain injury. Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data collection:** Focus groups **Analysis:** Thematic analysis	• Access to support for social participation ○ Acceptability - Attitudes of others ○ Availability - Inpatient and outpatient sexual rehabilitation - Staff and resources ○ Accessibility - Discussions on intimacy and sexual well-being ○ Integrating sexual rehabilitation ○ Provision of information - Information for sexual rehabilitation
Freeman 2020 Phenomenological UK **Aim** To explore the experiences and views of social isolation in people with multiple sclerosis.	N=16 adults with multiple sclerosis CND category: Progressive neurological disease Age in years [Mean (SD)]: Not reported, age range 38-72 Sex (M/F): n=7/n=9	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Acceptability - Complex application process - Support in group environments ○ Availability - Community activities and groups

Study	Participants	Methods	Themes applied after thematic synthesis
			- Perceived availability - Staff and resources ○ Accessibility - Travel concerns and physical barriers
Gibbs 2022 General qualitative inquiry UK **Aim** To explore the experiences of people with acquired brain injury when participating in a surfing intervention, and to suggest possible mechanisms for a resulting improvement in well-being.	N=15 adults with acquired brain injury CND category: Acquired brain injury Age in years [Mean (SD)]: 42.4 (12.88) Sex (M/F): n=10/n=5	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Acceptability - Support in group environments
Hooson 2013 Phenomenological UK **Aim** To explore which factors help to support return to work for people experiencing multiple impairments and disabilities after traumatic brain injury.	N=10 adults with traumatic brain injury CND category: Acquired brain injury Age in years [Mean (SD)]: 43.1 (13.75) Sex (M/F): n=8/n=2	**Data collection:** Semi-structured interviews **Analysis:** Interpretative phenomenological analysis	• Access to support for employment: ○ Acceptability - Early provision of vocational rehabilitation - Group settings - Length of rehabilitation intervention ○ Accessibility - Referral from other specialties - Support from unpaid carers ○ Integration (including communication) ○ Provision of information - Employment options ○ Personalisation of rehabilitation goals - Setting rehabilitation goals

Study	Participants	Methods	Themes applied after thematic synthesis
			- Workplace assessments
Hoskin 2021 General qualitative inquiry UK and Denmark **Aim** To explore and compare the experiences of young men with Duchenne muscular dystrophy in Denmark with those in England, when transitioning to adulthood. Note: The experiences of participants in Denmark are outside of protocol population and have not been extracted or analysed.	N=24 young men with Duchenne muscular dystrophy CND category: Progressive neurological disease Age in years [Mean (SD)]: Not reported, age range 14-47 Sex (M/F): n=24/n=0	**Data collection:** Focus groups and semi-structured interviews **Analysis:** Thematic analysis	• Access to support for employment ○ Accessibility - Bias and assumptions ○ Provision of information - Employment options • Access to support for social participation ○ Acceptability - Support in group environments ○ Accessibility - Discussions on intimacy and sexual well-being
Jarvis 2022 Case study UK **Aim** To explore healthcare professionals' experiences and views on implementing a regional multiple sclerosis pelvic health service, and provide lessons learned for future service provision.	N=5 healthcare professionals working with people with multiple sclerosis CND category: Progressive neurological disease Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Availability - Staff and resources ○ Accessibility - Discussions on intimacy and sexual well-being ○ Integrating sexual rehabilitation
Jellie 2014 General qualitative inquiry (within mixed-methods study) UK **Aim** To explore people's experiences while	N=19 adults with multiple sclerosis CND category: Progressive neurological disease Age in years [Mean (SD)]: Not reported, median 40, age range 24-63	**Data collection:** Semi-structured interviews **Analysis:** Constant comparative thematic analysis	• Access to support for employment: ○ Provision of information - Available support (including government assistance and legal protection) ○ Information for employers

Study	Participants	Methods	Themes applied after thematic synthesis
completing a vocational rehabilitation intervention designed for people with multiple sclerosis, and identify which factors were the most helpful.	Sex (M/F): n=4/n=15		○ Personalisation of rehabilitation goals - Workplace assessments
Jones 2019 General qualitative inquiry UK **Aim** To explore the experiences of people with Huntington's disease and service providers when co-producing a walking group for people with Huntington's disease.	N=6 people with Huntington's disease plus social care professionals CND category: Progressive neurological disease **People with Huntington's disease, n=3** Age in years: Not reported Sex (M/F): n=2/n=1 **Social care professionals working with people with Huntington's disease, n=3** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation: ○ Acceptability - Support in group environments ○ Availability - Community activities and groups ○ Accessibility - Travel concerns and physical barriers
Kelly 2023 General qualitative inquiry UK **Aim** To explore the experiences and views of young people re-engaging in physical leisure activities after acquired brain injury.	N=7 young people with acquired brain injury CND category: Acquired brain injury Age in years [Mean (SD)]: Not reported, age range 14-19 Sex (M/F): n=5/n=2	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Acceptability - Attitudes of others ○ Availability - Equipment and home adaptations ○ Accessibility - Travel concerns and physical barriers

Study	Participants	Methods	Themes applied after thematic synthesis
Learmonth 2013 General qualitative inquiry (within mixed-methods study) UK **Aim** To explore the experiences of people moderately impaired by multiple sclerosis taking part in a group exercise intervention and the consequences of participating in exercise and group exercise, and identify internal and external barriers to participating in exercise.	N=14 adults with multiple sclerosis CND category: Progressive neurological disease Age in years [Mean (SD)]*: • Focus group A: 54.2, (SD not reported), age range 45-62 • Focus group B: 51.0, (SD not reported), age range 40-68 Sex (M/F): n=4/n=10 *Only reported by focus groups, not for whole sample	**Data collection:** Focus groups **Analysis:** Thematic content analysis	• Access to support for social participation ○ Acceptability - Attitudes of others - Support in group environments ○ Availability - Community activities and groups ○ Accessibility - Travel concerns and physical barriers
Mullin 2018 Grounded theory UK **Aim** To explore the factors influencing workplace success (including relationships with employers and the provision of reasonable adjustments) in people with Parkinson's disease.	N=17 adults with Parkinson's disease CND category: Progressive neurological disease Age in years [Mean (SD)]: Not reported, median 53.5, age range 39-77 Sex (M/F): n=9/n=8	**Data collection:** Semi-structured interviews **Analysis:** Grounded theory	• Access to support for employment ○ Acceptability - Group settings - Visibility of adjustments ○ Availability - Support networks within the workplace ○ Accessibility - Bias and assumptions - Line managers as gatekeepers ○ Provision of information - Available support (including government assistance and legal protection) - Information for employers
Salas 2021 General qualitative inquiry UK **Aim**	N=12 adults with traumatic brain injury CND category: Acquired brain injury Age in years [Mean (SD)]: 49 (9.2)	**Data collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Access to support for social participation ○ Acceptability - Support in group environments

Study	**Participants**	**Methods**	**Themes applied after thematic synthesis**
To explore the reasons of people with chronic traumatic brain injury for attending Headway and their experiences of activities offered by the centre, and to propose a theoretical long-term social rehabilitation programme model for traumatic brain injury.	Sex (M/F): n=10/n=2		
Simpson 2020 General qualitative inquiry (within mixed-methods study) UK **Aim** To explore the views of people with motor neurone disease and social prescribing link workers on barriers and facilitators to implementing an intervention to support psychological wellbeing and decrease social isolation.	N=9 adults with motor neurone disease plus healthcare professionals CND category: Progressive neurological disease **Adults with motor neurone disease, n=5** Age in years [Mean (SD)][*]: 56 (SD not reported), age range 40-79 Sex (M/F): n=2/n=3 **Healthcare professionals working with people with motor neurone disease, n=4** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported [*]Unclear whether these figures are for the 5 interview participants or the 9 participants included in the full intervention study.	**Data collection:** Interviews (no further details reported) **Analysis:** Thematic analysis	• Access to support for social participation ○ Acceptability - Attitudes of others ○ Availability - Community activities and groups - Equipment and home adaptations - Staff and resources ○ Accessibility - Travel concerns and physical barriers
Taylor 2011	N=23 adults with motor neurone disease plus their partners	**Data collection:** Conversational interviews	• Access to support for social participation

Study	Participants	Methods	Themes applied after thematic synthesis
Phenomenological study UK **Aim** To explore the experiences of people with motor neurone disease as well as their feelings about how their condition has impacted their sexual expression and intimacy. To also explore the meaning of sexuality and intimacy and identify recommendations for healthcare professionals.	**Adults with motor neurone disease, n=13** CND category: Progressive neurological disease Age in years [Mean (SD)]: Not reported, age range 32-82 Sex (M/F): n=8/n=5 **Partners of people with motor neurone disease, n=10** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Analysis:** Hermeneutic phenomenological analysis	○ Acceptability - Electronic voices ○ Accessibility - Discussions on intimacy and sexual well-being
Thrussell 2018 Phenomenological UK **Aim** To explore women's experience of sexuality after spinal cord injury, including rehabilitation services and management of the practical aspects.	N=27 adult women with spinal cord injury CND category: Acquired spinal cord injury Age in years [Mean (SD)]: Not reported, age range 21-72 Sex (M/F): n=0/ n=27	**Data collection:** Semi-structured interviews **Analysis:** Thematic content analysis	• Access to support for social participation ○ Availability - Inpatient and outpatient sexual rehabilitation
Tresman 2016 General qualitative inquiry UK **Aim** To explore the experiences of parents of children with medulloblastoma plus healthcare and	N=27 parents of children and young people with medulloblastoma plus healthcare and education professionals CND category: Acquired brain injury **Parents of children and young people**	**Data collection:** Survey with free-text questions, semi-structured interviews, and focus groups **Analysis:** Thematic analysis	• Access to support for education ○ Acceptability - Timeliness of support ○ Integration (including communication) - Collaboration between healthcare and education

Study	Participants	Methods	Themes applied after thematic synthesis
education professionals about return to education after treatment. These views would inform a protocol for reintegration to improve the consistency of support offered.	**with medulloblastoma, n=9** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported, median 12.7 Sex of children and young people with chronic neurological disorders (M/F): n=7/ n=2 **Rehabilitation professionals working with children and young people with medulloblastoma, n=6** Age of children and young people with chronic neurological disorders in years: Not reported Sex of children and young people with chronic neurological disorders: Not reported **Education professionals working with children and young people with medulloblastoma, n=12** Age of children and young people with chronic neurological disorders in years: Not reported Sex of children and young people with chronic neurological disorders: Not reported		- Communication from education to rehabilitation professionals - Named contact - Sharing information within education settings o Sustainability - Emerging and changing support needs - Repetition of information o Transition o Advocacy - Parents or carers as advocates

1 *CND: chronic neurological disorder; SD: standard deviation*

See the full evidence tables in appendix D. As this was a qualitative review, no meta-analysis was conducted (and so there are no forest plots in appendix E).

Summary of the evidence

Themes and sub-themes for each qualitative review follow the same alphanumeric naming convention, with the first letter relating directly to the review letter (in this case ‘K’) and subsequent numbers relating to the order of main themes and sub-themes within the review. In this review, the evidence is summarised separately for education, employment and social participation. The GRADE-CERQual tables are organised in the same way.

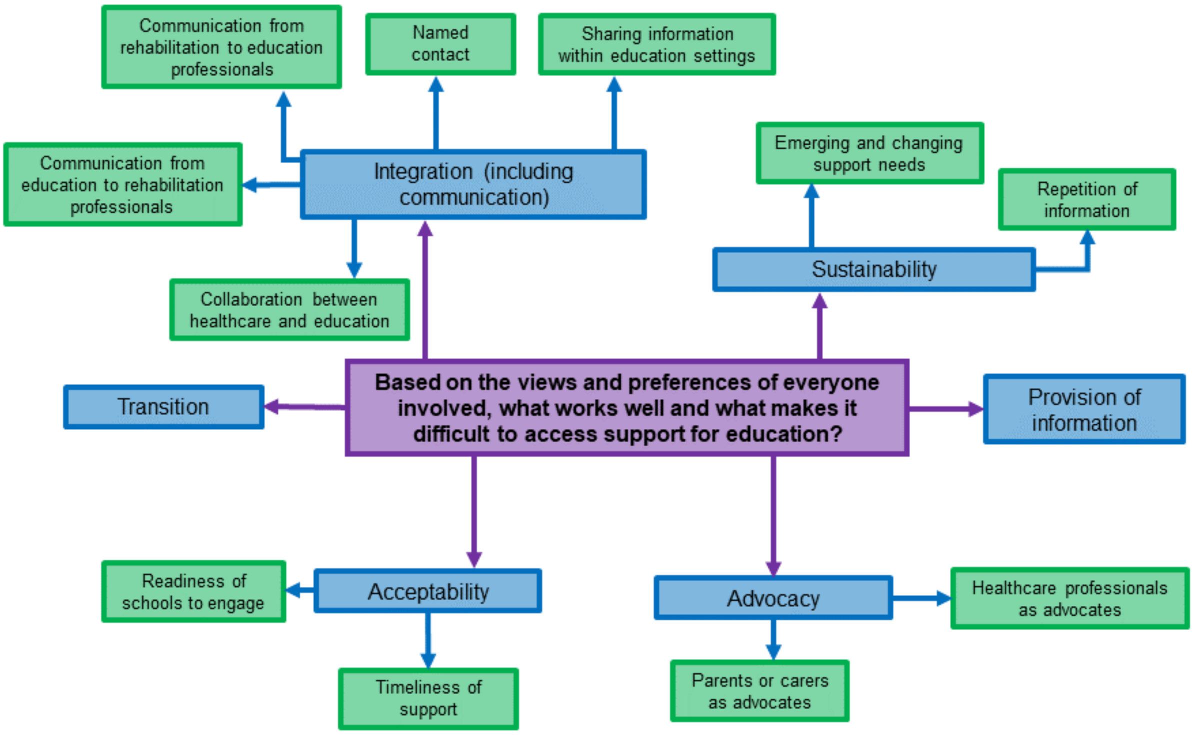
Access to support for education

The synthesis of the evidence generated the following 6 main themes:

- K1 Acceptability
- K2 Integration (including communication)
- K3 Provision of information
- K4 Sustainability
- K5 Transition
- K6 Advocacy

The theme map illustrates the main themes (shown in blue) and their related sub-themes (shown in green).

Figure 1: Theme map for what works well and what makes it difficult to access support for education



K1 Acceptability

Two sub-themes were identified under the theme of acceptability. In the ‘K1.1 Readiness of schools to engage’ sub-theme (very low confidence), evidence from 1 study showed that access to educational support was affected by the school’s readiness to engage with the young person's needs. In the 'K1.2 Timeliness of support' sub-theme (low confidence), evidence from 2 studies showed that parents were frustrated with the length of time it took to receive and implement an education care plan for their child.

K2 Integration (including communication)

Five sub-themes were identified under this theme. In the 'K2.1 Collaboration between healthcare and education' sub-theme (low confidence), evidence from 2 studies showed that access to support for education could be improved by increasing collaboration between education and healthcare professionals (for example, through in-person joint meetings). In the 'K2.2 Communication from education to rehabilitation professionals' sub-theme (low confidence), evidence from 2 studies showed that education professionals could increase their knowledge of education support options and ensure support needs were addressed in a timely manner by communicating with rehabilitation teams. In the 'K2.3 Communication from rehabilitation to education professionals' sub-theme (low confidence), evidence from 1 study showed that education settings needed communication from healthcare professionals to understand a child's education support needs and recommendations on what to put in place for them. In the 'K2.4 Named contact' sub-theme (very low confidence), evidence from 1 study showed that it would be helpful for education professionals to have a named hospital contact they could approach with specific questions and advice. In the 'K2.5 Sharing information within education settings' sub-theme (very low confidence), evidence from 1 study showed that a lack of information sharing within education settings left parents and healthcare professionals having to repeat information and explanations.

K3 Provision of information

In this theme (very low confidence), evidence from 1 study showed that children and young people needed information about available options and adjustments for supporting their education and rehabilitation needs. No sub-themes were identified for this theme.

K4 Sustainability

Two sub-themes were identified under the theme of sustainability. In the 'K4.1 Emerging and changing support needs' sub-theme (very low confidence), evidence from 1 study showed that long-term follow-up is needed when re-entering education, in order to address any evolving or new support needs. In the 'K4.2 Repetition of information' sub-theme (low confidence), evidence from 2 studies showed that information about chronic neurological disorders and resulting educational support needs may need to be repeated several times throughout the young person's education.

K5 Transition

In this theme (low confidence), evidence from 2 studies showed that transitioning between education settings can result in information being lost (for example, when support needs are not communicated to a new school). To minimise this, parents often had to be actively involved during this period.

K6 Advocacy

Two sub-themes were identified under the theme of advocacy. In the 'K6.1 Healthcare professionals as advocates' sub-theme (low confidence), evidence from 2 studies showed that healthcare professionals can be effective advocates for educational support needs. In the 'K6.2 Parents or carers as advocates' sub-theme (moderate confidence), evidence from 2 studies showed that parents and carers felt that they needed to be advocates for their child, in order to ensure that support needs were identified and plans were developed to address them.

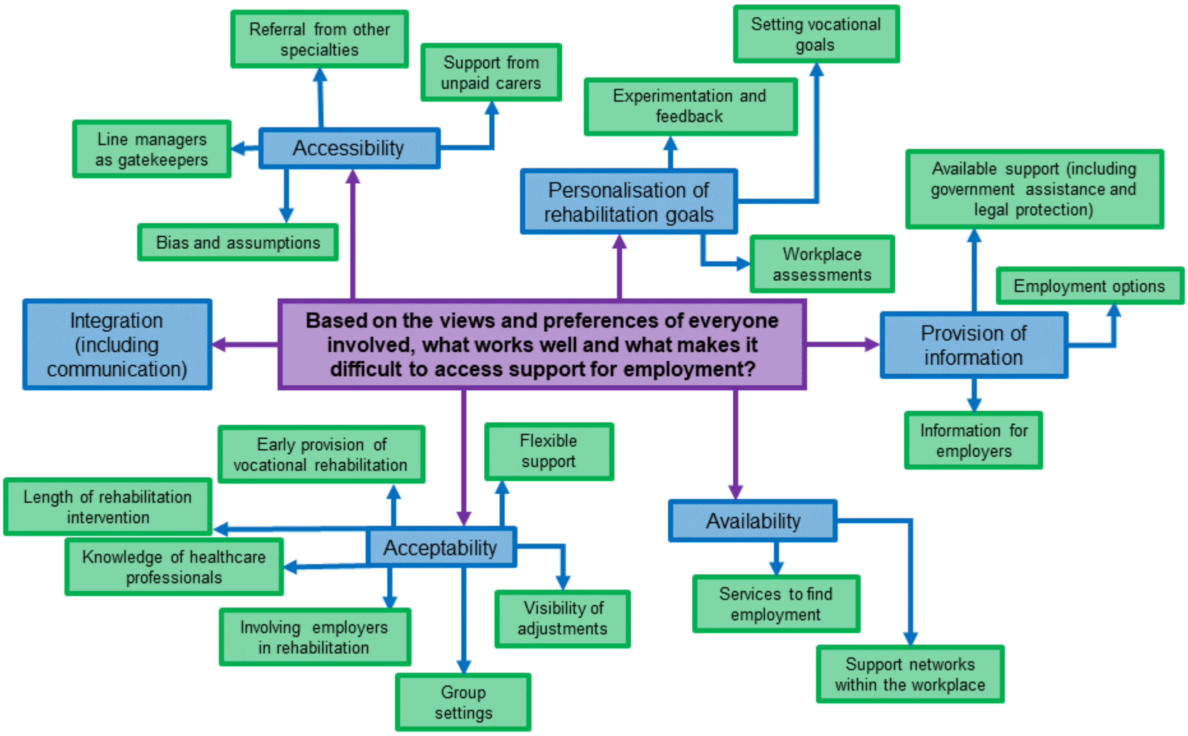
Access to support for employment

The synthesis of the evidence generated the following 6 main themes.

- K7 Acceptability
- K8 Availability
- K9 Accessibility
- K10 Integration (including communication)
- K11 Provision of information
- K12 Personalisation of rehabilitation goals

The theme map illustrates the main themes (shown in blue) and their related sub-themes (shown in green).

Figure 2: Theme map for what works well and what makes it difficult to access support for employment



K7 Acceptability

Seven sub-themes were identified under the theme of acceptability. In the ‘K7.1 Early provision of vocational rehabilitation’ sub-theme (moderate confidence), evidence from 2 studies showed that vocational rehabilitation should begin as soon as possible after diagnosis in order to increase awareness of support and tailor rehabilitation to the individual’s needs. In the ‘K7.2 Flexible support’ sub-theme (low confidence), evidence from 1 study showed that flexible delivery of vocational rehabilitation was critical to increasing access to support. In the ‘K7.3 Group settings’ sub-theme (low confidence), evidence from 1 study showed that some people found group delivery of vocational rehabilitation increased engagement with the intervention and improved socialisation for people with chronic neurological disorders. In the ‘K7.4 Involving employers in rehabilitation’ sub-theme (moderate confidence), evidence from 2 studies showed that people with chronic neurological disorders were unsure about including employers in their rehabilitation, as a large concern of theirs was managing relationships with employers and colleagues. In the ‘K7.5 Knowledge of healthcare professionals’ sub-theme (low confidence), evidence from 1 study showed that the vocational rehabilitation knowledge of healthcare professionals was important for them to have confidence offering employment advice when needed. In the ‘K7.6 Length of rehabilitation intervention’ sub-theme (moderate confidence), evidence from 2 studies showed that vocational interventions should be offered for a longer period of time. In the ‘K7.7 Visibility of adjustments’ sub-theme (moderate confidence), evidence from 1 study showed that people with chronic neurological disorders preferred using adaptive equipment that did not draw attention to their disabilities.

K8 Availability

Two sub-themes were identified under the theme of availability. In the ‘K8.1 Services to find employment’ sub-theme (very low confidence), evidence from 1 study showed that personalised and individual support can help people better overcome practical barriers to working. In the ‘K8.2 Support networks within the workplace’ sub-theme (low confidence), evidence from 1 study showed that formal internal company support networks for people with chronic neurological conditions can help support people in requesting reasonable adjustments in the workplace, as well as offering peer support.

K9 Accessibility

Four sub-themes were identified under the theme of accessibility. In the ‘K9.1 Bias and assumptions’ sub-theme (low confidence), evidence from 3 studies showed that people with chronic neurological disorders were less likely to be provided with information on or support for employment due to people assuming they would not be able to do certain things. In the ‘K9.2 Line managers as gatekeepers’ sub-theme (moderate confidence), evidence from 2 studies showed that line managers often controlled whether and how people accessed reasonable adjustments in the workplace. In the ‘K9.3 Referral from other specialities’ sub-theme (low confidence), evidence from 2 studies showed that access to vocational rehabilitation is increased when healthcare professionals can identify potential vocational rehabilitation concerns and refer to appropriate specialists when needed. In the ‘K9.4 Support from unpaid carers’ sub-theme (low confidence), evidence from 1 study showed the importance of family members in helping people with chronic neurological disorders access support for employment rehabilitation.

K10 Integration (including communication)

In this theme (high quality), evidence from 3 studies showed that healthcare professionals should collaborate with other professionals (including human resources and legal representatives) in order for people with chronic neurological disorders to access appropriate employment rehabilitation options. The presence of a rehabilitation professional within a workplace also increases how serious employers take reasonable adjustment requests. No sub-themes were identified for this theme.

K11 Provision of information

Three sub-themes were identified under the theme of provision of information. In the ‘K11.1 Available support (including government assistance and legal protection)’ sub-theme (high confidence), evidence from 2 studies showed that people with chronic neurological disorders may need education about the vocational support options available to them when in employment. In the ‘K11.2 Employment options’ sub-theme (moderate confidence), evidence from 3 studies showed that people needed to be provided with information on what different work options are accessible to them, and the advantages and disadvantages of them. In the ‘K11.3 Information for employers’ sub-theme (moderate confidence), evidence from 3 studies showed that providing employers with information on an individual’s rehabilitation needs was important for them engaging in the rehabilitation process. However, healthcare professionals should be careful about what information they share, as some people may not want to disclose all information on their prognosis to their employer.

K12 Personalisation of rehabilitation goals

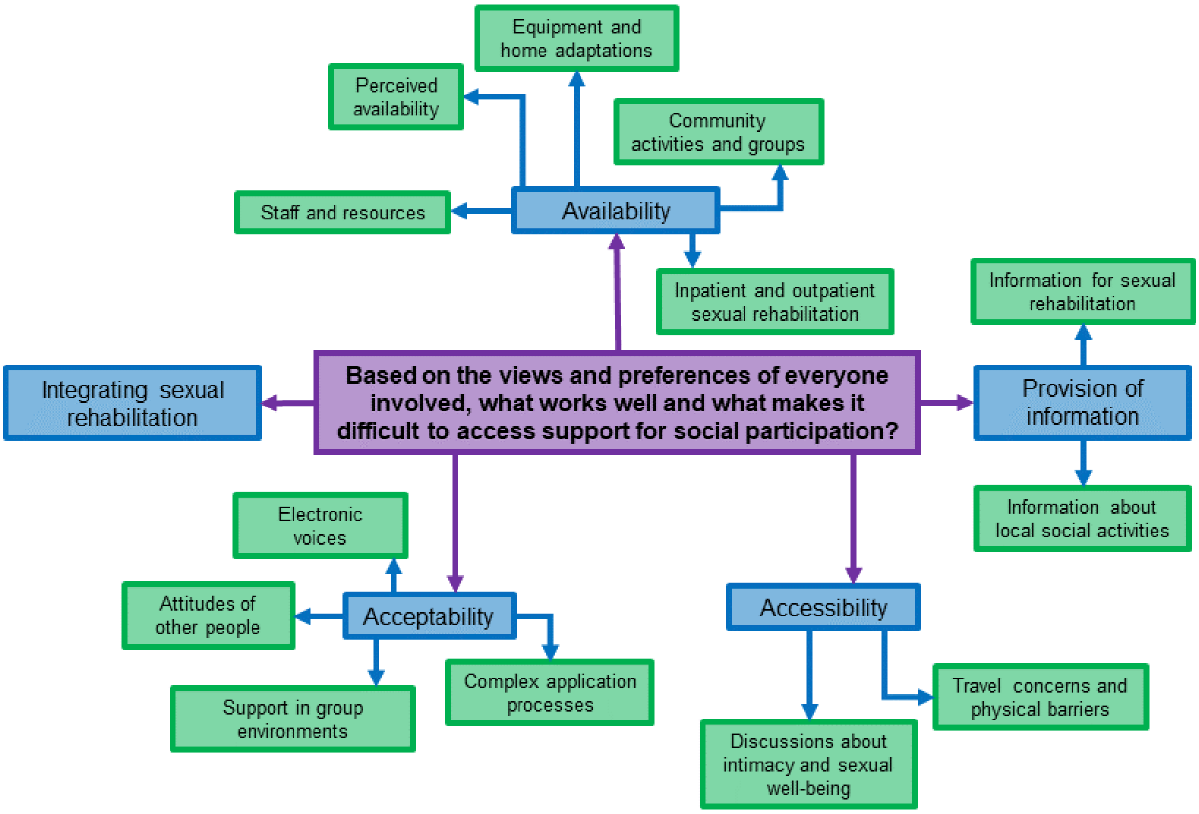
Three sub-themes were identified under this theme. In the ‘K12.1 Experimentation and feedback’ sub-theme (moderate confidence), evidence from 2 studies showed that people with chronic neurological disorders appreciated having the opportunity to experiment and adjust work adaptation strategies in real-life work environments. In the ‘K12.2 Setting vocational goals’ sub-theme (low confidence), evidence from 2 studies showed that realistic and achievable employment goals were important in engaging people in vocational rehabilitation, and that healthcare professionals should assist them in this process. In the ‘K12.3 Workplace assessments’ sub-theme (high confidence), evidence from 3 studies showed that workplace assessments were very beneficial in identifying rehabilitation needs and providing in-person support for vocational rehabilitation.

Access to support for social participation

The synthesis of the evidence generated the following 5 main themes.

- K13 Acceptability
- K14 Availability
- K15 Accessibility
- K16 Integrating sexual rehabilitation
- K17 Provision of information

The theme map illustrates the main themes (shown in blue) and their related sub-themes (shown in green).



K13 Acceptability

Four sub-themes were identified under the theme of acceptability. In the ‘K13.1 Attitudes of other people’ sub-theme (low confidence), evidence from 5 studies showed that access to support for social participation can be both positively and negatively affected by other people’s attitudes. Examples of positive impacts were when healthcare professionals assisted in identifying suitable activities for people to participate in or when teachers encouraged participation in new hobbies. Examples of negative impacts were when people with chronic neurological disorders had concerns about an individual’s knowledge of their condition. In the ‘K13.2 Complex application processes’ sub-theme (moderate confidence), evidence from 1 study showed that people with chronic neurological disorders were less likely to access government schemes to support social participation if the application process was confusing, as if often was. In the ‘K13.3 Electronic voices’ sub-theme (low confidence), evidence from 1 study showed that electronic voice software was an unhelpful support for participation in personal relationships because it decreases intimacy. In the ‘K13.4 Support in group environments’ sub-theme (moderate confidence), evidence from 7 studies showed that some people with chronic neurological disorders appreciated participating in group activities due to the peer support, camaraderie and chance to form new friendships. However, others did not appreciate group settings when conversations covered sensitive topics or when there was a wide variety of needs within the group.

K14 Availability

Five sub-themes were identified under the theme of availability. In the ‘K14.1 Community activities and groups’ sub-theme (high confidence), evidence from 4 studies showed that geographical barriers, poor resources and lack of appropriate options all contributed to a lack of availability of community activities and groups. In the ‘K14.2 Equipment and home adaptations’ sub-theme (low confidence), evidence from 2 studies showed that people with chronic neurological disorders were frequently unable to participate in social activities due to a lack of equipment and home adaptations. In the ‘K14.3 Inpatient and outpatient sexual rehabilitation’ sub-theme (moderate confidence), evidence from 3 studies showed that people with chronic neurological disorders reported poor availability of sexual rehabilitation services at all stages of rehabilitation, which was exacerbated by healthcare professionals’ lack of knowledge on the subject (including about referral options for sexual rehabilitation). In the ‘K14.4 Perceived availability’ sub-theme (low confidence), evidence from 1 study showed that people with chronic neurological disorders often did not access support for social participation because they believed that services were too busy to help, or that their needs were not a high priority. In the ‘K14.5 Staff and resources’ sub-theme (moderate confidence), evidence from 5 studies showed that people with chronic neurological disorders were less likely to participate in social and community participation when support was not sufficient or inconsistent.

K15 Accessibility

Two sub-themes were identified under the theme of accessibility. In the ‘K15.1 Discussions on intimacy and sexual well-being’ sub-theme (high confidence), evidence from 7 studies showed the people with chronic neurological disorders were not asked about their sexual well-being and functioning despite them being open to discussing the topic. Healthcare professionals were reticent to initiate these conversations for a variety of reasons and would appreciate training on starting sensitive conversations. In the ‘K15.2 Travel concerns and physical barriers’ sub-theme (moderate confidence), evidence from 6 studies showed that reduced transportation options and a lack of awareness of reduced mobility experienced by people with chronic neurological disorders reduces access to venues to encourage social participation.

K16 Integrating sexual rehabilitation

In this theme (moderate confidence), evidence from 4 studies showed that sexual functioning measures are rarely included in standardised assessments, which means that it can be overlooked in subsequent rehabilitation planning. Including these measures in assessments can facilitate better integration of sexual rehabilitation in standard care. No sub-themes were identified for this theme.

K17 Provision of information

Two sub-themes were identified under the theme of provision of information. In the ‘K17.1 Information about local social activities’ sub-theme (very low confidence), evidence from 1 study showed that people with chronic neurological disorders were often unaware of what social activities were available to them in the local area. In the ‘K17.2 Information for sexual rehabilitation’ sub-theme (moderate confidence), evidence from 3 studies showed that people with chronic neurological disorders receive much less information about sexual rehabilitation compared to other areas of rehabilitation. It was suggested that providing reading materials could help people to consider their sexual rehabilitation needs.

See appendix F for full GRADE-CERQual tables.

Economic evidence

Included studies

In the development of this qualitative review, targeted searches for evidence on cost effectiveness were planned. The committee was asked to consider whether a recommendation represents a substantial change in practice and results in significant resource impact and if so targeted searches around that area would be undertaken. The committee could not identify a recommendation that would benefit from targeted searches for the supporting economic evidence.

Excluded studies

No economic searches were undertaken for this qualitative review.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

The committee’s discussion and interpretation of the evidence

The outcomes that matter most

To address the question of what works well and what makes it difficult to access support for education, employment, and social participation, this review was designed to include qualitative data. As a result, the committee could not specify in advance the data that would be identified. Instead, they agreed, by informal consensus, on the following main themes to guide the review, although the list was not exhaustive, and the committee were aware that additional themes could be identified:

- Acceptability. For example, people’s opinions about how access is affected by the way in which support is provided, including methods of provision, timeliness of support, and practicality of options for people using services.

- Availability. For example, people’s experiences of the availability of support, including local rehabilitation resources, specialist neurological services. Other examples could include experiences about opening times, appointment systems and eligibility criteria.
- Accessibility. For example, people’s experiences of the accessibility of clubs and societies (for example, after-school activities or sports teams).
- Integration (including communication). For example, opinions on how integration and communication between rehabilitation services and education, employment and community or leisure services affects access to support.
- Equalities considerations. For example, the extent to which support services are perceived to address equalities considerations, including support for people whose first language is not English, cultural sensitivity or age appropriateness.
- Provision of information. For example, the availability of information about how chronic neurological disorders may affect education/employment/social participation, the support available to them, or legal support requirements.
- Personalisation of rehabilitation goals. For example, people’s views about whether accessing support enables the fulfilment of their own personalised goals for a return to employment, education, or broader social participation.
- Sustainability. For example, how people with relapsing-remitting chronic neurological disorders can access and re-access support services.
- Transition. For example, views on the ease of access to support for people with chronic neurological disorders when changing jobs or transitioning between educational settings.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall confidence in the findings for the qualitative review ranged from very low to high.

The review findings were generally downgraded due to concerns over the methodological limitations of included studies (for example, poor reporting of recruitment methods or a lack of consideration given to the relationship between researcher and participants), concerns over coherence of themes (for example when a theme was constructed from positive and negative aspects of a finding), and concerns over adequacy (for example, when only 1 study contributed to a theme, or when contributing studies did not have rich data). Studies were not downgraded due to relevance concerns.

Anticipated themes that were set out in the protocol but not reported by any studies include:

- Equalities considerations

Themes for which evidence was reported but had not been set out in the protocol:

- Advocacy
- Integrating sexual rehabilitation

See appendix F for full GRADE-CERQual tables with quality ratings of all review findings.

Benefits and harms

Designing and commissioning rehabilitation services

Building local capacity and expertise

Moderate quality evidence from the sub-theme ‘K13.4 Support in group environments’ reported mixed evidence on the use of group settings to facilitation social participation in the community setting. While some people found groups to be beneficial (for example, offering peer support), others felt as though collective environments were inappropriate (for example, feeling they were being reduced to a disorder). The committee’s experience corresponded with both the positive and negative aspects of this theme, particularly how some people with progressive neurological disorders may feel being part of a group with people who were further along the disease course. They discussed that, for people who found group settings to be helpful for continued social participation, this service should be available to them and funding should be allocated as such. However, they highlighted that this does not have to take the form of traditional disorder-specific groups and that people should have the option to try work out which (if any) group they would prefer to join. For example, children and young people may prefer to socialise with people of the same age, even if groups are not specifically targeted towards young people with chronic neurological disorders. Furthermore, the committee caveated that group settings may not be suitable for people with functional neurological disorders, as continued socialising with people exhibiting symptoms can exacerbate a condition and prolong recovery. The committee agreed that commissioners should consider funding a flexible range of local social and leisure groups, and that these should be designed based on feedback from the local population and the principles of this recommendation, rather than assumptions about the sorts of groups that people with chronic neurological disorders would like to attend.

Assessing rehabilitation needs and goal setting

Goal setting

For education, training and work

Low quality evidence from the theme ‘K12.2 Setting vocational goals’ showed that setting realistic vocational rehabilitation goals helps to increase engagement, but rehabilitation professionals often need to help set expectations with these goals to prevent them from being too advanced for a person’s abilities. Additional moderate quality evidence from the theme ‘K12.1 Experiment and feedback’ showed that people with chronic neurological disorders valued the opportunity to trial adaptations and amend strategies through feedback. The committee agreed with both these themes and recommended that rehabilitation professionals work with people to identify their vocational rehabilitation goals and review these whenever general rehabilitation needs are being reviewed. Regular reviewing gives people the opportunity to feedback on what has and what hasn’t worked since their previous appointment and amend rehabilitation needs and goals accordingly. The committee also recommended preceding setting rehabilitation goals with gathering information on an individual’s aspirations, which will greatly impact on what goals are set. Although similar themes were not identified in regard to access to support for education, from the committee’s experience and expertise these considerations should also apply when setting educational goals. They therefore expanded this section of recommendations to include education, and included likely developmental trajectory as a consideration when setting rehabilitation goals (especially as this will help to inform realistic goals). While similar recommendations have been made regarding general rehabilitation goals for chronic neurological disorders, the committee discussed that this need to develop realistic goals is especially important for vocational and educational rehabilitation, where additional fears (for example, finances) may encourage people to try accomplishing too much too quickly.

Rehabilitation planning and delivery

Agreeing and delivering a coordinated rehabilitation plan

The committee discussed the importance of ensuring collaboration extends outside of healthcare services for the components of a rehabilitation plan that will include employment and education (including adult education) sectors. This was supported by separate themes identified in the access to support for education and access to support for employment sections of this question. Very low quality evidence from the theme ‘K1.1 Readiness of schools to engage’ suggests that access to educational support is positively correlated with engagement from educational establishments. Low quality evidence from the theme ‘K2.1 Collaboration between healthcare and education’ showed that collaboration between these 2 services helped to increase efficiency of education support provision. Similarly, moderate quality evidence from the theme ‘K7.4 Involving employers in rehabilitation’ showed that that involving employers in rehabilitation planning provided opportunities to discuss and set expectations on what adjustments people with chronic neurological disorders need to continue with their employment. The committee recommended that through this collaborative effort consideration should be given to what rehabilitation interventions are needed, how they might be delivered, and in what context they will be used. This will be different for each individual, and will need to take into account the person, their diagnosis, their prognosis, and each environment they will encounter.

The committee discussed very low quality evidence from the theme ‘K4.1 Emerging and changing needs’, which showed the importance of long-term follow-up to address emerging and changing educational support needs. Although this evidence was identified in children and young people, the committee reflected that this was also an underserved area for adults who are continuing, returning to, or entering education, and especially true in people with progressive or fluctuating conditions. If education support plans are not current, then emerging and changing rehabilitation needs will not be documented and are at risk of being overlooked. This will inevitably increase the challenges for adults with chronic neurological disorders to engage in their education. Therefore, the committee recommended regularly reviewing education support plans for adults to ensure that adjustments are still appropriate and a person’s needs are still being met.

Information, advice and learning as part of rehabilitation

The committee discussed very low quality evidence from the theme ‘K8.1 Services to find employment’, which showed that personalised and one-to-one support is effective to identify barriers to employment. This was supported by moderate quality evidence from the theme ‘K11.2 Employment options’ which showed that people were unaware of what work options were available to them, including self-employment. Further low quality evidence from the theme ‘K7.5 Knowledge of healthcare professionals’ showed that it is very important that healthcare professionals have knowledge of vocational rehabilitation, disorder specific challenges, and legal protections. While the committee agreed with these themes, they also noted the resource implications of recommending individually delivered vocational rehabilitation compared to the low quality evidence and lack of cost-effectiveness evidence. Instead, they added employment and legal support as an area in which people should be provided with personalised information including how to get advice. However, they noted that this is not the only area where personalised information would be helpful. Using their experience and expertise, they expanded this list to include education, housing, benefits and wider legal support. Please note that this recommendation also uses evidence from evidence review B, where the remainder of the committee’s discussion can be found.

Low quality evidence from the theme ‘K14.2 Equipment and home adaptations’ and moderate quality evidence from the theme ‘K15.2 Travel concerns and physical barriers’ showed that access to social participation was hindered by a lack of available equipment (for example, people unable to leave their homes without wheelchairs), home adaptations, and transportation options. Further moderate quality evidence from the theme ‘K13.2 Complex application processes’ showed that applying to government schemes to assist social participation was often complicated and bureaucratic, and made more confusing by cognitive symptoms experienced by many in this population. The committee agreed with these findings, stating that there is funding available to help people access these services, but it is often poorly advertised and not easy to complete. Therefore, they recommended that options for financial support be explained to people with chronic neurological disorders, so they are informed of their options and how to start the application process.

The committee also discussed the difficulties of a person disclosing their condition and rehabilitation needs in all areas of their life, which is a common occurrence. Although not expressly identified in the evidence, this apprehension was echoed by themes mentioning internal biases, pre-conceived notions of ability and worries of discrimination throughout this evidence review. The committee discussed that, while it is important to recommend ways of decreasing barriers (which they have done in other areas of this guideline), it is important to simultaneously increase an individual's confidence in communicating information on their disorder and their resulting rehabilitation needs. Within NHS settings, the committee highlighted that the use of disability passports can help with this. Socially, communication can range from how to request adjustments within community settings to informing friends and acquaintances. The committee noted that this preparation should also include consideration of what information people do not want to share, so they do not feel pressurised to do so when situations arise.

Rehabilitation to maintain, improve or support function

Speech, language and communication

Low quality evidence from the theme 'K13.3 Electronic voices' showed that electronic assistive equipment was too robotic to adequately convey emotions. While the committee agreed that electronic voices were not perfect, they can still be beneficial in helping people communicate in certain situations. Creating a personalised synthetic voice can be a way of decreasing the robotic nature of electronic voice, making it sound closer to an individual's natural voice. Due to the expense of this process, the fact it may not be suitable for everyone, and the conflict between the evidence and the committee's experience, the committee did not recommend that this is offered to people with chronic neurological disorders. However, they noted that this process requires people to bank their voices, which has long waiting times. By offering an early referral to this service for people who are or who are likely to experience voice loss due to their condition, healthcare professionals can start the lengthy process while still giving people enough time to think about the personal advantages and disadvantages of creating a personalised synthetic voice outside of the NHS.

Environmental adaptations, assistive technology and equipment

The committee discussed high quality evidence from the theme 'K11.1 Available support (including government assistance and legal protection)', which showed that people with chronic neurological disorders were not always informed about government assistance and legal protections while in the workforce. The committee recognised this from their experience and recommended that people be supported to access funding for support in their workplace, allowing them to advocate more efficiently for these adaptations. Alongside this finding, the committee considered moderate quality evidence from the theme 'K14.5 Staff and resources', which showed that people were left unable to participate in social interactions due to poor availability of resources. While the committee did not feel able to make a recommendation about increasing the level of support a person with a chronic neurological disorder should receive due to the inevitable resource impact, they did recommend that people be given advice and support about what funding is available for equipment and adaptations around the home, education and workplace settings that might help people with participation in these areas. Examples of this funding include the disabled facilities grant, local authority needs assessments and care plans, access to work grants, voluntary sector grants and funding from the Department for Work and Pensions. Please note that this recommendation also uses evidence from evidence review B, where the remainder of the committee's discussion can be found.

Rehabilitation to support education, work, social and leisure activities, and relationships

Rehabilitation to support education for children and young people

The committee discussed the importance of education for children and young people with chronic neurological conditions, noting that it is a human right enshrined in articles 28 and 29 of the UN Convention on the Rights of the Child. Furthermore, in the UK it is a legal requirement for children or young people to have access to education that is suitable to their age, ability, aptitude, and any special educational need that they may have (Sections 7 and 19, Education Act 1996). Finally, apart from the formal education aspect, school attendance is important for language skills, peer relationships, shaping identities, developing resilience, and forming social and emotional bonds.

Low quality evidence from the theme ‘K1.2 Timeliness of support’ showed that early and focused information on education support needs helps to put adjustments in place as early as possible, preferably before a child has to return to school. Low quality evidence from the theme ‘K2.3 Communication from rehabilitation to education professionals’ showed that healthcare professionals are important in helping education professionals better understand these support needs and their own role within a child’s rehabilitation. The committee agreed with these findings and recommended that the responsible clinician (usually the professional making the provisional diagnosis or diagnosis), working together with parents and carers, begins this collaboration by informing education settings of a diagnosis as soon as possible. While more information (for example, specific and actionable education needs adjustments) may not be available at this time, the committee argued that the knowledge that these will need to be considered in future can help them prepare to some extent.

Once a likely prognosis is determined and rehabilitation needs are assessed, this should also be communicated to the education setting. However, this should not simply be provision of information. The committee agreed with low quality evidence from the theme ‘K2.1 Collaboration between healthcare and education’ which showed that a lack of collaboration between the 2 services led to poor implementation of educational support. They therefore clarified that healthcare professionals should have conversations with education providers, with the aim of understanding needs and negotiating adjustments and provisions to help children with these needs.

Very low quality evidence from the theme ‘K2.4 Named contact’ showed that a specific healthcare contact can be helpful for education settings, especially if they are concerned or have questions about rehabilitation needs. Despite the low quality of the evidence, this finding agreed with the committee’s expertise and experience. They noted that this contact is a valuable tool in implementing the information sharing and collaboration stated in the preceding recommendations. Encouraging continuity of contact for education providers increases the possibility of a good working relationship between the 2 services. The committee discussed the evidence on the importance of rehabilitation professionals communicating with educational professionals alongside additional low quality evidence from the theme ‘K2.2 Communication from education to rehabilitation professionals’, which showed that communication in the other direction (that is, from education to healthcare) was important (for example, to allow reporting of worsening symptoms or perhaps additional educational concerns). Therefore, the committee recommended that communication and information sharing between these services is reciprocal and ongoing. The committee went on to discuss low quality evidence from the theme ‘K5 Transition’, which showed that information on education support needs is often lost during periods of transition due to poor communication within education services. This was strengthened by very low quality evidence from the theme ‘K2.5 Sharing information within education settings’ and very low quality evidence from the theme ‘K3 Provision of information’. These findings showed inefficient communication within education settings meant that education support needs were not always relayed to the most appropriate member of staff within that setting. The committee agreed with this, stating that a common example of this poor communication was when children or young people transferred between key education stages. The committee therefore highlighted the importance of communication and information sharing during periods of transition to support continuity of access and stressed that this should apply to everyone involved in supporting the child or young person’s continuing education (that is, within and between services). Finally, the committee discussed low quality evidence from the theme ‘K4.2 Repetition of information’ showed that it can be helpful for information to be repeated, especially if there is a lot provided at once. While the committee did not disagree with this theme, they had concerns that a recommendation advising repetition of information could entrench disjointed communication methods and increase the risk of contradictory information being shared. However, they noted that promoting two-way communication and building good relationships between education and rehabilitation professionals will also give the opportunity for people to easily request a repeat of information if they feel it would be helpful.

The committee discussed very low quality evidence from the theme ‘K4.1 Emerging and changing needs’, which showed that long-term follow-up is needed to address emerging and changing educational support needs. Although the quality of the evidence was poor, the committee argued that every child and young person will face changing education support needs throughout their time in education. This is exacerbated by the presence of a chronic neurological disorder, particularly if it is a progressive or fluctuating condition. Children and young people may require alternative education provision including schools for children and young people with additional needs. The committee therefore recommended regularly checking for the appropriateness of current education settings and provision, as well as specific rehabilitation needs within education, health and care plans. This process should be iterative, encouraging feedback from all participants (the child or young person, parents or carers, rehabilitation professionals, and education professionals), to form a complete picture of education needs and adjustments.

Rehabilitation and the workplace

Please note that the following discussion of the evidence applies to both paid and voluntary work.

Although not covered by this review question, the committee discussed the importance of assessment in accessing support for employment, as this helps to determine an individual’s baseline abilities and expectations for vocational rehabilitation. Using the committee’s experience and expertise, they highlighted 3 areas that should be considered when undertaking this assessment in order to ensure that rehabilitation goals and interventions are planned appropriately. Firstly, how much of their previous skills have been retained, and what are their continued strengths and motivations. Secondly, what their prognosis is. The committee discussed that while many people will experience a reduction in rehabilitation needs with time, other people (for example, those with progressive neurological conditions) may experience more severe rehabilitation needs due to advancing symptoms.

The committee discussed an important consideration within vocational rehabilitation for chronic neurological disorders, that returning or remaining in the same job may not be the best option for some individuals. Some people may wish to change career after their injury or diagnosis, or leave the work force entirely. Both processes require information and support.

The committee discussed moderate quality evidence from the theme ‘K7.1 Early provision of vocational rehabilitation’, which showed that, in order to increase access to employment, discussions surrounding vocational rehabilitation should begin as soon as possible after diagnosis. Further moderate quality evidence from the theme ‘K7.4 Involving employers in rehabilitation’ showed that including employers in rehabilitation planning allowed all parties to negotiate support needs and set expectations of what return-to-work might look like. The committee agreed with both pieces of evidence but noted that, in their experience and expertise, vocational rehabilitation should be offered from initial presentation of symptoms and impairments as there may be a considerable delay between this and receiving an official diagnosis. Therefore, they recommended that these talks with individuals and employers about remaining or returning to work start as early as feasible, with this also providing an opportunity to educate employers and help to interpret medical reports. They noted that the information discussed and adjustments agreed in these early discussions will differ between individuals. For example, a person recently diagnosed with multiple sclerosis may need far less immediate employment support compared to someone with a recent traumatic brain injury. High quality evidence on the theme ‘K12.3 Workplace assessments’ showed the importance of carrying out a detailed workplace assessment to correctly identify these barriers to return-to-work in the first place, communicate the most appropriate strategies to lessen them, and provide in-person support to implement them. The committee therefore recommended considering a workplace capacity evaluation to inform these discussions. The committee also agreed with high quality evidence from the theme ‘Integration (including communication)’, which showed appropriate access to and implementation of vocational support requires collaboration with other employment professionals outside of direct teams and management structures. Therefore, the committee included involving specific workplace professionals (for example, occupational health team, human resources and legal teams) when needed in these discussions. The committee were aware of further detailed guidance in identifying, reviewing and managing return-to-work in recommendation 1.16.4 in NICE’s guideline on adult stroke rehabilitation. Despite this population being out of scope for this guideline, the committee argued that it was applicable for the larger population of people with chronic neurological disorders and referred readers to it. Returning to the theme ‘K12.3 workplace assessments, the committee discussed their experiences with these. They agreed that assessments should focus both on the functional capacity of the person to undertake work-based tasks but also on the environmental, cultural and procedural barriers that the workplace may now present to the person. Workplace assessments should therefore focus on identifying solutions or strategies for both the person and the employer to act upon in seeking to overcome barriers and enable the person to stay in or return to work.

The committee discussed moderate quality evidence from the theme ‘K11.3 Information for employers’ which showed that, although there were benefits to educating employers on chronic neurological conditions and vocational rehabilitation needs, some individuals were concerned that disclosing too much information could lead to discrimination. The committee were sympathetic to this fear and noted that in their experience it was not unfounded. However, due to the range of conditions, rehabilitation needs, safety considerations, and individual levels of comfort with disclosure that would need to be covered, they were not confident detailing the information that employers should not receive.. The committee also considered moderate quality evidence from the theme ‘K7.7 Visibility of adjustments’, which showed that people with chronic neurological disorders were self-conscious if they felt as though their workplace adjustments drew attention to their disability. Combining evidence from the 2 themes, the committee recommended that people should be consulted on what workplace adjustments they would like to receive, as well as the level of confidentiality and privacy they would like regarding these.

The committee discussed the importance of context when assessing and delivering vocational rehabilitation. A busy office environment will present different cognitive and sensory challenges to people with chronic neurological disorders than a sterile clinical setting, and delivering rehabilitation interventions in the workplace will allow for a more real-world application and learning process. However, a clinical setting might be more suitable by minimising distraction for people who are learning skills for the first time. Therefore, the committee recommended healthcare professionals use whatever context is the most appropriate for an individual, their rehabilitation needs, and goals.

The committee discussed the need for regular review of vocational rehabilitation needs, as these can fluctuate, perhaps even more so than other rehabilitation needs. Including employers means that people will face additional pressures and priorities from management, which could conflict with what is best for their rehabilitation. For example, increased workloads may lead to increased challenges with fatigue. Therefore, they recommended that vocational rehabilitation needs to be reviewed at the same time as other rehabilitation needs, so that vocational rehabilitation becomes a core component of any rehabilitation assessment and plan. Similarly, the committee agreed that implementation of reasonable adjustments should be checked, as this is rarely completely correct the first time and may need several rounds of implementation and feedback before it is effective. Additionally, adjustments will have to be amended in line with changing rehabilitation needs. The committee stressed that communication about rehabilitation needs should continue through the entire rehabilitation process, and any changes should be communicated to the employer to action. The committee discussed the fact that many conditions covered by this guideline will face fluctuating and sometimes increasing rehabilitation needs (for example, those with progressive conditions). The committee recommended that employers be proactive rather than reactive in checking back with the person regularly about any changing or anticipated future needs. Where specialist health or care advice is needed, healthcare practitioners should be involved in discussions to ensure plans are appropriate. Alongside these recommendations, the committee discussed moderate quality evidence from the theme 'K7.6 Length or rehabilitation intervention', which showed that vocational rehabilitation should last until no further barriers can be identified. The committee agreed that the non-specific nature of this finding meant it was not suitable as a basis for a direct recommendation, but that the future-proofing aspect of the theme was adequately covered by this recommendation.

Participating in social and leisure activities

The committee discussed low quality evidence from the theme 'K13.1 Attitudes of other people' which showed that access to support for social participation could be both positively and negatively impacted by other people's actions. Negative actions could include psychosocial barriers (for example, believing healthcare professionals were uninterested) or practical barriers (for example, healthcare professionals not completing risk assessments). This finding reflected the committee's own experience and expertise, and they therefore recommended discussing potential barriers to social participation with people with chronic neurological disorders, as well as strategies to address or reduce them. The committee also wanted to highlight a common barrier that they encounter, which was professionals' pre-conceived ideas of what goals should look like. A central aim of social participation is to allow people with chronic neurological disorders to make and maintain relationships, so social participation rehabilitation goals can often be simple and everyday activities. Alongside this theme, the committee also discussed very low quality evidence from the theme 'K17.1 Information about local social activities', which showed that people were not aware of what local social groups were active and accessible to them. Despite the quality of the evidence, this finding reflected the committee's experience and they recommended that people are informed and encouraged to explore local clubs and social activities. These clubs may or may not in specific to people with chronic neurological disorders. Additional moderate quality evidence from the theme 'K13.2 Complex application processes' showed that people found it difficult to complete applications for funding to access social participation, which could be exacerbated by cognitive symptoms of their disorder. The committee used this theme, along with the difficulties in completing risk assessments that was mentioned in 'K13.1 Attitudes from other people' to recommend that people with chronic neurological disorders receive assistance with completing paperwork required for them to participate in social activities. The committee were aware that this sort of paperwork is often completed by general practitioners, but stressed that any health care or social care professional (including social prescribing link workers) can assist with this process.

The committee discussed an often overlooked barrier to social participation, which is disclosure of their condition and having conversations about their necessary adjustments and adaptations. These conversations need to be had with organisers in order to explain necessary adjustments and adaptations but they can often be emotional, with people being unaware of what information they should or should not be relaying, or even what they do and do not want to divulge. Therefore, the committee recommended that people be supported (for example, by a advocate, support worker or family member) to have these discussions in order to still access their preferred community activities. Another area that is commonly neglected in people with chronic neurological disorders is concerns over toilet access. People within this population are more likely to have issues with bladder and/or bowel incontinence, which can lead to them being uncomfortable exploring social participation opportunities outside of familiar environments. The committee discussed that this issue is further compounded by embarrassment (from both people with chronic neurological disorders and professionals involved in their care) in discussing the topic. Therefore, the committee wanted to highlight toilet needs and access as an area to address when planning travel, social and leisure activities.

Finally, the committee discussed high quality evidence from the theme ‘K.14.1 Community activities and groups’ which showed that access to community activities and groups was decreased due to poor availability of these services. Despite the quality of evidence, the committee was reticent to make a recommendation on this finding as service needs would vary widely depending on the local community and the inevitable resource impact, making crafting a national recommendation impossible. However, they were aware that many groups and activities are delivered at least partially online, especially since COVID-19. Therefore, they recommended considering these online options for people facing geographical barriers to accessing suitable social forums.

Family life and friendships

The definition of support for social participation used in this guideline includes supporting participation in meaningful activity or occupations such as parenting, caring, family and friendships. While no specific themes were identified for these areas, the committee acknowledged that people with chronic neurological disorders face additional challenges fulfilling these social roles (for example, decreased mobility limiting the ability to socialise in public spaces or managing fatigue with caring responsibilities). They also highlighted the well documented benefits associated with developing and maintaining all different forms of relationships, namely on mental health, well-being, and quality of life. Therefore, all recommendations in this section were made using the committee’s expertise and experience.

The committee discussed that goals relating to family life and friendship should be treated in the same way as any other rehabilitation objective, and professionals should encourage discussion around these areas in order to correctly identify and develop these goals and the rehabilitation approaches and interventions that would support them. As part of this, professionals should ask about important relationships in a person’s life. Not only will this help to further elaborate the rehabilitation goal, but it also prevents assumptions about what relationships are most important to the person. Similarly, healthcare professionals should also ask individuals to talk though their thoughts and feelings about the future and how changing needs (especially for people with progressive conditions) may impact on family life and friendships in the future. The committee went on to discuss that, in order to develop appropriate and realistic rehabilitation goals and put in place the correct rehabilitation approaches and interventions, current or potential barriers to participation should be identified and addressed as part of rehabilitation planning. As family life and friendships infuse every part of a person’s life, the committee highlighted that these barriers can be inter-related, complex, and varied. They also noted that this should be a recurring process, built into assessment, goal setting and planning. Finally, the committee discussed the specific rehabilitation needs and goals that accompany parenting and caring roles. People with chronic neurological disorders that are also parents and or carers face additional emotional and physical demands that need to be factored into rehabilitation goal setting and planning. Parents and carers with chronic neurological disorders are at an increased risk of needing to access parent support services (for example, local authority children and family services) while facing increased barriers to doing so. Therefore, healthcare professionals should aim to enable access to these services. Parents and carers may also need targeted rehabilitation interventions to strengthen their parenting or caring skills (for example, caring for a newborn baby and breastfeeding).

Intimate and sexual relationships and sex

The committee discussed moderate quality evidence from the theme ‘K17.2 Information for sexual rehabilitation’, which showed that support for intimacy and sexual rehabilitation is adversely impacted by a lack of information. This was supported by moderate quality evidence from the theme ‘K14.3 Inpatient and outpatient sexual rehabilitation’, showing that there was a lack of education and information about sexual rehabilitation within rehabilitation services. The committee agreed that there was a lack of information on intimate and sexual relationships and sexual rehabilitation when compared to other areas of physical functioning areas. They also noted that, even if this information was available, it was poorly promoted to people with chronic neurological disorders. The committee highlighted 2 examples of how services could better promote and provide information on intimacy and sexual rehabilitation. Firstly, healthcare settings should clearly display information, for example visibly showing pamphlets or posters. Some people may prefer to read the information and reflect on their potential rehabilitation needs, before raising this subject with their rehabilitation professional in their own time. Secondly, in the committee’s experience, having practical aids and equipment for demonstrations alongside discussions can help initiate conversations, answer questions, and better inform decision making.

High quality evidence from the theme ‘K15.1 Discussions on intimacy and sexual well-being’ gave detailed data showing that sexual needs were often not captured in rehabilitation plans because questions on intimacy and sexual well-being often went unasked. People with chronic neurological disorders were open to having these conversations but found it difficult to raise the subject. The committee recommended that people be encouraged to have these conversations by providing an opportunity for discussion, which can then be used to set rehabilitation goals in this area and plan rehabilitation interventions accordingly.

The committee went on to discuss further detail from the finding ‘K15.1 Discussions on intimacy and sexual well-being’ that rehabilitation professionals reported they did not feel comfortable initiating conversations as they did not feel they have the knowledge of sexual rehabilitation or training in sensitive conversations to do so. The committee agreed that poor confidence in a rehabilitation area does mean healthcare professionals are less likely to bring up the topic. They therefore recommended that rehabilitation professionals are proactive in decreasing their discomfort in discussing intimacy and sexual rehabilitation, noting that this could be done through expanding their clinical knowledge or their confidence in having sensitive conversations. Additional moderate quality evidence from the theme ‘K14.3 Inpatient and outpatient sexual rehabilitation’ showed a lack of knowledge amongst healthcare professionals regarding sexual rehabilitation, including who to refer to if the subject was raised. The committee agreed that there is a limit to the education that non-specialist rehabilitation professionals are expected to obtain. In this case, the committee recommended that professionals should at least be aware of the services to which they should refer people. The committee also acknowledged that the area of intimate relationships, sexual relationships and sex raises concerns over safeguarding and consent. Healthcare professionals should be aware that these concerns are especially significant in 2 sub-groups covered by this guideline: people who lack the ability to give consent; and children and young people. If issues are suspected, professionals should ensure that they know who to seek advice from or signpost to.

The committee discussed that, while recommendations in this section are meant to decrease barriers when discussing intimacy and sexual relationships, these conversations are still sensitive in nature and very personal. Healthcare professionals should consider individual characteristics such as a person’s gender identify, sexual orientation, religion, and cultural beliefs. This will help to increase the levels of comfort and trust during discussions, increasing the chance for open and honest conversations. It will also ensure that assessment identifies the correct barriers and increases the effectiveness of any interventions. The committee also noted that to develop appropriate and realistic rehabilitation goals, barriers to intimate or sexual relationships should be identified. As intimacy and sexuality are so personal, the committee highlighted that these barriers can range from physical to communication to social.

The committee discussed that people talk about intimacy and sexual functioning in different ways. Some people may not appreciate a lengthy in-person discussion to gather initial information, certainly before they have time to process their prognosis, thoughts or goals for the future. Therefore, the committee recommended that healthcare professionals use their experience to gather baseline information and concerns in an appropriate manner. An example to give people time to collect their thoughts would be to give a self-reported questionnaire ahead of appointments, so people can consider their answers before having an in-person discussion.

The committee discussed an often overlooked barrier for sexual rehabilitation, which is when and how to discuss their disorder and its impact on intimacy, sex and sexual functioning with current or future partners. As mentioned previously, conversations about sex and intimacy are personal and open communication can be difficult. When including a potential partner, emotional barriers can be even harder to overcome. Healthcare professionals should support people with chronic neurological disorders in having these conversations with current or future partners (for example, working with individuals to identify what information they are comfortable sharing, and how to do this).

The committee discussed the best way to address any rehabilitation needs that are identified during these discussions and assessment. They agreed that targeting rehabilitation could assist people with physical and psychological issues surrounding sex and intimacy after diagnosis or injury. Similarly, providing information can help educate people on their disorders and suggest adjustments that can be made. The committee noted that, in many cases, training for current or potential partners will be needed to implement rehabilitation interventions (for example, sexual aids) and advice (for example, positioning). Finally, some people with chronic neurological disorders will need aids and equipment. These can either be provided outright, or may be obtained through signposting to other services. As this guideline covers all settings, the committee discussed additional barriers surrounding sex and intimacy faced by people with chronic neurological disorders within some residential settings. For example, people in residential care may experience lack of privacy if they are unable to lock their bedroom door or be unable to access pornography due to restrictions on their internet access. The committee recommended that these potential barriers be addressed if possible, although they were aware that sometimes patient safety might prevent this.

Application of recommendations across the guideline population

Finally, the committee considered the breadth of the conditions included in this guideline and discussed whether these recommendations could be applied to all of them. As the recommendations are written at a high level and do not include references to specific interventions, the committee were confident that they would be applicable to all chronic neurological disorders included by this guideline.

There were a number of themes identified in this review that the committee did not use to inform specific recommendations. The committee discussed low quality evidence from the theme ‘K6.1 Healthcare professionals as advocates’ which showed the healthcare professionals can play a vital role in advocating for children and young people’s education support needs. There was also a complementary moderate quality theme, ‘K6.2 Parents of carers as advocates’, that showed parents often have to advocate for their children when it comes to education support needs for chronic neurological diseases, and needed adequate information in order to adequately fulfil this role. The committee agreed with both of these themes but were aware that recommendations about how parents, carers and healthcare professionals were already covered in greater detail in the NICE guideline on babies, children and young people’s experiences of healthcare. This guideline has been referenced in order to help better set the context of how rehabilitation for children and young people with chronic neurological disorders should best be delivered. Low quality evidence from the theme ‘K7.2 Flexible support’ showed that flexibility was key in delivering effective vocational rehabilitation and to allow as many people as possible to access support. The committee agreed with this evidence, but noted that they had already made several recommendations on flexible rehabilitation delivery within the guideline section ‘Managing and coordinating rehabilitation (including over a person’s life course)’. These recommendations extend to vocational rehabilitation. Low quality evidence from the theme ‘K7.3 Group settings’ showed that group settings can help engagement in vocational rehabilitation by adding a social and peer support element. While the committee did agree that social and peer support can facilitate rehabilitation, they were concerned about the feasibility of making a recommendation with this evidence. In their experience, vocational rehabilitation is not only individualised to a person but also to a workplace and duties. This would make forming appropriate groups difficult, if not impossible, for most services to implement. Additionally, the committee have made general recommendations on using group settings in the guideline section covering participation in social and leisure activities, which will allow people to experience the peer support detailed by this finding. Low quality evidence from the theme ‘K8.2 Support networks within the workplace’ showed that formalised support networks within companies were helpful in helping people with chronic neurological disorders to access support for employment in the workplace, but that provision of these were sporadic. Further low quality evidence from the theme ‘K9.1 Bias and assumptions’ showed that internal biases and assumptions about what people with chronic neurological disorders can achieve in the workplace may affect the level of support that they are offered in the workplace. This was supported by additional moderate quality evidence from the theme ‘K9.2 Line managers as gatekeepers’ showed that immediate line managers were key to helping or blocking access to reasonable requirements in organisations. The committee agreed with all 3 findings, noting that creating an open, flexible, and proactive workplace culture and policies was an important factor in ensuring people with chronic neurological disorders are able to access the support they need to return to and stay in the workplace if they so wish. However, the committee were aware that recommendations on this subject already exist and instead referred readers to the NICE guideline on workplace health: long-term sickness absence and capability to work at the end of the section on ‘Rehabilitation and the workplace’. The committee discussed low quality evidence from the theme ‘K9.3 Referral from other specialties’ which showed that access to support for vocational rehabilitation could be improved by individual rehabilitation specialists identifying challenges and barriers to employment and referring them on to appropriate services. The committee did not use this finding to inform any recommendations as it suggests that rehabilitation specialists should have knowledge of symptoms and barriers outside their area of practice. However, the committee were confident that their recommendations about what to include in a holistic assessment detail the need to concentrate on all aspects of a person’s rehabilitation, not simply the symptoms they may be presenting with. The committee discussed low quality evidence from the theme ‘K9.4 Support from unpaid carers’, which showed the importance of unpaid carers in supporting people to access vocational rehabilitation services. While the committee agreed with the value of unpaid carers, they did not use this finding to make any recommendations as they did not want to strengthen a narrative where people with chronic neurological disorders are expected to rely on informal support networks to access rehabilitation services. Low quality evidence from the theme ‘K14:4 Perceived availability‘ showed that people believed that rehabilitation services were not adequately resourced to providing support for social participation. As this finding is related to people’s perceptions of service availability, it is difficult to address with recommendations. However, the committee discussed that they have made recommendations about including social participation in the holistic rehabilitation assessment, as well as providing information on support to access social participation, which should address this belief within people with chronic neurological disorders. Moderate quality evidence from the theme ‘K16 Integrating sexual rehabilitation’ showed that sexual rehabilitation is rarely included alongside other areas of functioning in standardised assessments from the beginning of rehabilitation planning. The committee agreed that intimacy and sexual rehabilitation was often only addressed later in recovery and rehabilitation, despite it being a very important area for people’s personal relationships and quality of life. They had previously made several recommendations about what to include in a holistic assessment based on qualitative evidence from evidence review C, and therefore simply ensured that intimate and sexual relationships and sex was adequately highlighted within this section so as not to be overlooked during initial rehabilitation discussions and assessments, and carried through to rehabilitation planning.

Cost effectiveness and resource use

For this qualitative review, the committee could not identify a recommendation that would benefit from targeted searches for supporting economic evidence, therefore there was no existing evidence on the cost effectiveness. The committee based their recommendations on their collective experience and expertise, reflecting current best practices for most services.

Designing and commissioning rehabilitation services for complex and long-term needs

The committee discussed local social and leisure groups to support community rehabilitation and social participation for people with chronic neurological disorders. They noted variations in practice and potential additional resources needed to establish these groups where they do not exist and to ensure activities cater to different needs. The committee discussed that reducing isolation and improving wellbeing can decrease healthcare utilisation by preventing, for example, mental health deterioration and the need for crisis intervention. It also promotes independence, potentially reducing the need for formal caregiving. Therefore, in their view such groups are likely to represent a cost-effective use of healthcare resources.

Intimate relationships, sexual relationships, and sex as components of the holistic assessment

Incorporating intimate and sexual relationship discussions into holistic assessments may require more healthcare practitioner time. This could lead to more people being identified with related needs and accessing treatments and services. Although intimacy and sexual rehabilitation are currently discussed, it often occurs later in the process. There may be some resource implications, but these are not expected to be significant.

Education or training goals

There is variation in practice regarding goal setting for education, training and work. The lack of related services means these aspects of rehabilitation are inconsistently discussed and addressed. Ensuring timely and appropriate consideration of these aspects of rehabilitation may have resource implications, as might the increased demand for related support services. However, the committee noted that goal setting for education, training and work can promote independence and reduce reliance on more intensive and costly services in the long run. It may also increase the likelihood of returning to education or work or engaging in volunteering activities, resulting in broader social and economic benefits.

Collaboration with other services

Currently, there is variation in how rehabilitation services engage with employment and education sectors. Resources may be needed to facilitate a comprehensive approach addressing health, educational and vocational needs. The committee highlighted the importance of these aspects for outcomes of people with chronic neurological disorders, including mental health, social participation, and feeling valued members of society. Such a collaborative approach may improve the chances of people returning to work or participating in vocational activities, offering broader social and economic benefits.

Equipment and home adaptations

The committee noted that funding for various equipment and home adaptations is available, but these specialist services are underused due to a lack of awareness. The recommendations may lead to increased referrals to these services. However, as these services are already funded by NHS England, this will not increase costs.

Communication and rehabilitation needs

There may be an increase in referrals for voice banking for individuals likely to experience voice loss. This process typically takes a few hours and is usually provided outside the NHS at a personal cost or funded by Personal Independence Payment (PIP).

Rehabilitation and education for children and young people

The recommendation to inform the relevant education setting after suspecting or diagnosing a chronic neurological disorder in a child or young person, and to ensure two-way communication and information sharing between healthcare and education practitioners, reinforces current best practices. There may be some resource implications where practices are sub-optimal. However, the committee noted that some of these could be implemented using low-cost strategies. For example, ongoing communication could be achieved cost effectively by having a named healthcare practitioner. Therefore, they did not expect this recommendation to have significant resource implications.

Overall, the committee was of a view that any additional costs associated with implementing recommendations on rehabilitation and education for children and young people would be offset by the return to and retention of children and young people in education, along with the associated benefits of improved social participation, health and wellbeing, and broader social and economic benefits.

Rehabilitation and the workplace

The committee acknowledged significant variation in the delivery of vocational rehabilitation services, noting that these services are often unavailable. They highlighted that occupational therapists work closely with employers, potentially presenting more opportunities for those seeing occupational therapists.

The committee recognised the potential resource implications of setting up new vocational rehabilitation services. Given the financial constraints on the NHS and the lack of evidence on effectiveness and cost effectiveness, they focused their recommendations on existing vocational services. As a result of the recommendations, there may be a slight reconfiguration of existing services, but this is expected to be done within existing funding, with no significant resource implications for the NHS expected.

Recommendations such as recording employment history, incorporating vocational goals into rehabilitation plans, and educating healthcare professionals about vocational rehabilitation may require more healthcare practitioner time. Therefore, implementing these recommendations may require some additional resources where such practices are not routine.

The committee discussed that effective vocational rehabilitation requires collaboration between employers, occupational health consultants, occupational therapists, physiotherapists and advocates for people with chronic neurological disorders. It was noted that current email communications between parties are often inefficient. The committee suggested that a few face-to-face meetings could be a more efficient and cost-effective way to facilitate collaborative working.

The committee highlighted that healthcare professionals need more education about the roles and responsibilities of different agencies and available services. This could involve directing them to existing educational resources, such as free e-learning modules on partnership working and resources for general practitioners and employers. This will ensure people are directed to appropriate services that meet their vocational rehabilitation goals and contribute to their overall wellbeing.

Participating in social and leisure activities

The committee explained that practices vary in supporting people's social participation. They noted that recommendations in this area represent good practices and should be standard for most services. However, additional resources, mainly staff time, may be required to implement these recommendations where practices are sub-optimal. This may include improving practices around exploring barriers to social participation, helping with risk assessments and form filling, and supporting individuals to explain any adjustments needed to access community venues.

Consistently enquiring about social participation issues may identify more people needing support. Services may also need to train staff to ensure they are confident, well-informed, and can provide accurate information and signposting to appropriate support services.

As a result of these recommendations, more people may access related support interventions and services. However, the committee discussed that social participation can sometimes be facilitated by simple activities, such as coffee with a friend or signposting to local clubs.

The committee noted variations in the availability of community activities, clubs and groups to support social participation and generally the lack of these. Additional resources may be needed to establish these where they do not exist. However, many available online options could mitigate the resource impact.

The committee also noted potential support through the WorkWell government initiative to help disabled people and those with health conditions start, stay, and succeed in work, and may make implementation easier.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.3.7, 1.9.9 to 1.9.12, 1.10.5 to 1.10.6 , 1.13.2, 1.13.6, 1.20.8, 1.22.8, 1.23.1 to 1.23.6, 1.24.1 to 1.24.9, 1.25.1 to 1.25.7, 1.26.1 to 1.26.3, and 1.27.1 to 1.27.11.

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Appendices

Appendix A Review protocols

Review protocol for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

Table 3: Review protocol

ID	Field	Content
0.	PROSPERO registration number	Not registered with PROSPERO as review does not contain any health outcomes.
1.	Review title	Access to education, employment, and social support for people with chronic neurological disorders.
2.	Review question	Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?
3.	Objective	• To establish the views and preferences of people with chronic neurological disorders, their families, and carers about what works well and what makes it difficult to access support for education, employment, and social participation. • To establish the views and preferences of practitioners in health and social care and those involved in education, employment, volunteering and leisure about what works well and what makes it difficult for people with chronic neurological disorders to access support for education, employment, and social participation.
4.	Searches	The following databases will be searched: • Medline All • Embase • Cochrane Database of Systematic Reviews (CDSR) • Social Policy and Practice • PsychInfo Searches will be restricted to:

ID	Field	Content
		• Date: 2010 - present • English language • Human studies • OECD Geographic filter (amended) Conference proceedings, editorials, case reports, new, historical articles and letters will be excluded Other searches: • Additional searching may be undertaken if required. With the agreement of the guideline committee the searches will be re-run 6 weeks before final submission of the review and further studies retrieved for inclusion. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Access to support for employment, education, and social participation for people with chronic neurological disorders.
6.	Population	**Inclusion:** • Adults and children with rehabilitation needs due to the following chronic neurological disorders: ○ Acquired brain injury ○ Acquired spinal cord injury ○ Acquired peripheral nerve disorders ○ Progressive neurological diseases ○ Functional neurological disorders • Family and carers of people with chronic neurological disorders. • Health and social care practitioners who work with people with chronic neurological disorders. • Other professionals involved in supporting education or employment of people with chronic neurological disorders **Exclusion:**

ID	Field	Content
		• Conditions which do not fit one of the 5 categories of chronic neurological disorder as defined in the guideline scope. These exclusions will be by exception and examined on a case-by-case basis rather than whole disorder groups. For example, this guideline will not cover autonomic neuropathy or the acute stabilisation of conditions such as encephalitis or hydrocephalus and will not cover degenerative disc disorder as spinal discs do not form part of the spinal cord. • Disorders for which interventions are primarily focused on altering body structure and functions, for example isolated peripheral nerve injuries, that is single nerve or plexus injuries. • Surgical management of conditions (for example brain tumours, orthopaedic complications). • Conditions for which NICE rehabilitation and rehabilitation related recommendations already exist, including stroke in people aged 16 years and over, dementia including Alzheimer's disease, cerebral palsy, myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome and post-COVID-19 syndrome. • Early rehabilitation after spinal cord injury as this will be covered in the NICE guideline on rehabilitation after traumatic injury
7.	Phenomenon of interest	The committee wish to locate qualitative evidence about what works well and what could be improved about access to support for education, employment, and social participation for people with chronic neurological disorders. They anticipate that data from included studies will cover a number of key themes although they are aware that other relevant themes may also be identified. Expected themes include: • **Acceptability.** Data may relate to opinions about how access is affected by the way in which support is provided, including, for example, methods of provision, timeliness of support, and practicality of options for people using services. • **Availability.** Data may relate to people's experiences of the availability of support, including, for example, local rehabilitation resources, specialist neurological services. Also, about opening times, appointment systems and eligibility criteria. • **Accessibility.** Data may relate to the accessibility of clubs and societies (for example, after-school activities or sports teams).

ID	Field	Content
		• **Integration (including communication).** Data may relate to how integration and communication between rehabilitation services and education, employment and community or leisure services affects access to support. • **Equalities considerations.** Data may relate to the extent to which support services are perceived to address equalities considerations, including, for example, support for people whose first language is not English, cultural sensitivity or age appropriateness. • **Provision of information.** Data may relate to the availability of information about how chronic neurological disorders may affect education/employment/social participation, the support available to them, or legal support requirements. • **Personalisation of rehabilitation goals**. Data may relate to people's views about whether accessing support enables the fulfilment of their own personalised goals for a return to employment, education, or broader social participation. • **Sustainability.** Data may relate to how people with relapsing-remitting chronic neurological disorders can access and re-access support services. • **Transition**. Data may relate to ease of access to support for people with chronic neurological disorders when changing jobs or transitioning between educational settings.
8.	Comparator/Reference standard/Confounding factors	Not applicable as this is a qualitative review.
9.	Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: data collection via focus groups, semi-structured and structured interviews, observations • Surveys conducted using open ended questions and a qualitative analysis of responses Note: Mixed-methods studies will be included but only qualitative data will be extracted and risk of bias assessed.
10.	Other exclusion criteria	Inclusion: • Full text papers • Studies conducted in the UK ○ If insufficient* UK data are available to support decision making about children and young people, then evidence from Australia, New Zealand and Canada will be considered.

ID	Field	Content
		*Sufficiency will be judged on considerations such as number of studies and size and breadth of population. Exclusion: • Articles published before 2010 • Papers that do not include methodological details will not be included as they do not provide sufficient information to evaluate risk of bias/ study quality. • Studies using quantitative methods only (including surveys that report only quantitative data) • Surveys using mainly closed questions or which quantify open ended answers for analysis. • Non-English language articles • Conference proceedings • Abstract only • Books, book chapters and theses Thematic saturation: 1. Data or theme(s) from included studies will not be extracted for particular theme(s) if thematic saturation is reached. 2. Papers included on full text will subsequently be excluded when the whole anticipated framework of phenomena (9 anticipated themes listed in row 7) has reached thematic saturation. That is, when evidence synthesis and the application of GRADE-CERQual show that data about all 9 aspects of the phenomenon of interest are ‘adequate’ and ‘coherent’. See row 7 above for details of the anticipated framework of phenomenon and associated rationale.
11.	Context	Settings: • Included: ○ All inpatient, outpatient and community settings in which either fully or partially publicly funded rehabilitation interventions for chronic neurological disorders are provided. • Excluded: ○ Accident and emergency departments.

ID	Field	Content
		○ Critical care units ○ Prisons
12.	Primary outcomes (critical outcomes)	Not applicable as this is a qualitative review. For anticipated themes, see row 7 above, ‘Phenomenon of interest’
13.	Secondary outcomes (important outcomes)	Not applicable as this is a qualitative review. For anticipated themes, see row 7 above, ‘Phenomenon of interest’
14.	Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into EPPI-Reviewer 5 and de-duplicated. • Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Dual sifting will be performed on at least 10% of records (or 300 records, whichever is smaller); 90% agreement is required and disagreements will be resolved via discussion with the senior systematic reviewer. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed along with the reason for its exclusion. • The included and excluded studies lists will be circulated to the Topic Group for their comments. Resolution of disputes will be by discussion between the senior reviewer, Topic Advisor and Chair. • A standardised form will be used to extract data from included studies, providing study reference, research question, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (that is, supporting quotes). One reviewer will extract relevant data into a standardised form. This will be quality assessed by the senior reviewer.
15.	Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) qualitative checklist, and systematic reviews of qualitative studies will be assessed using the CASP Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by the senior reviewer.
16.	Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes as ‘review findings’.

ID	Field	Content		
		• The GRADE-CERQual approach will be used to summarise the confidence in the review findings synthesized from the qualitative evidence (‘Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series’; Lewin 2018). • The overall confidence in evidence about each review finding will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance.		
17.	Analysis of sub-groups	As this is a qualitative review subgroup analysis is not possible. However, if data allow, the review will include information regarding differences in views held between certain groups, for example, the five identified ‘types’ of chronic neurological disorders. In these circumstances the committee will consider whether there is a case to make separate recommendations for different groups of for people in different circumstances.		
18.	Type and method of review	☐	Intervention	
		☐	Diagnostic	
		☐	Prognostic	
		☒	Qualitative	
		☐	Epidemiologic	
		☐	Service Delivery	
		☐	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	November 2021		
22.	Anticipated completion date	December 2023		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑	☑
		Piloting of the study selection process	☑	☑

ID	Field	Content		
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		Data analysis	☑	☑
24.	Named contact	**5a Named contact** National Institute for Health and Care Excellence (NICE) **5b Named contact e-mail** rehabforcnd@nice.org.uk **5c Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE)		
25.	Review team members	NICE review team		
26.	Funding sources/sponsor	This systematic review is being completed by NICE which receives funding from the Department of Health and Social Care.		
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of		

ID	Field	Content	
		Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10181/documents.	
29.	Other registration details	Not applicable	
30.	Reference/URL for published protocol	Not applicable	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords	Rehabilitation; Neurological disorders; Support; Employment; Education; Social participation; Chronic conditions; Qualitative.	
33.	Details of existing review of same topic by same authors	Not applicable	
34.	Current review status	☐	Ongoing
		☐	Completed but not published
		☒	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information	Not applicable	
36.	Details of final publication	www.nice.org.uk	

CASP: Critical skills appraisal programme; COVID-19: coronavirus; GRADE-CERQual: Grading of recommendations assessment, development and evaluation – confidence in the evidence from reviews of qualitative research; N/A: not applicable; OECD: Organisation for Economic Co-operation and Development; PROSPERO: International prospective register of systematic reviews

Appendix B Literature search strategies

Literature search strategies for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

Databases: Medline all

Date of last search: 04/08/2023

#	Searches
1	(CRANIOCEREBRAL TRAUMA/ or brain injuries/ or exp brain hemorrhage, traumatic/ or exp brain injuries, diffuse/ or exp brain injuries, traumatic/ or exp brain injury, chronic/ or Shaken Baby Syndrome/ or HYPOXIA, BRAIN/ or Brain Damage, Chronic/ or exp INTRACRANIAL HEMORRHAGE, TRAUMATIC/ or exp BRAIN NEOPLASMS/ or BRAIN DISEASES/ or BRAIN ABSCESS/ or BRAIN DISEASES, METABOLIC/ or CEREBELLAR DISEASES/ or cerebrovascular disorders/ or basal ganglia cerebrovascular disease/ or cerebrovascular trauma/ or intracranial arteriovenous malformations/ or "intracranial embolism and thrombosis"/ or intracranial hemorrhages/ or vascular headaches/ or exp ENCEPHALITIS/ or exp HYDROCEPHALUS/) not (exp STROKE/ or dementia/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	exp STROKE/ and (ADOLESCENT/ or MINORS/ or exp CHILD/ or exp INFANT/ or exp PEDIATRICS/ or exp PUBERTY/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	exp SPINAL CORD INJURIES/ or exp SPINAL CORD NEOPLASMS/ or EPIDURAL ABSCESS/ or SPINAL CORD DISEASES/ or exp SPINAL CORD VASCULAR DISEASES/ or SPINAL CORD COMPRESSION/ or MYELITIS, TRANSVERSE/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	PERIPHERAL NERVE INJURIES/ or exp CRANIAL NERVE INJURIES/ or PERIPHERAL NERVOUS SYSTEM NEOPLASMS/ or exp CRANIAL NERVE NEOPLASMS/ or exp PERIPHERAL NERVOUS SYSTEM DISEASES/ or exp CRANIAL NERVE DISEASES/
16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	exp MOTOR NEURON DISEASE/ or POSTPOLIOMYELITIS SYNDROME/ or exp PARKINSONIAN DISORDERS/ or MUSCULAR DYSTROPHY, DUCHENNE/ or exp MULTIPLE SCLEROSIS/ or NEUROMUSCULAR DISEASES/ or SPASTIC PARAPLEGIA, HEREDITARY/ or FRIEDREICH ATAXIA/ or exp MULTIPLE SYSTEM ATROPHY/ or SUPRANUCLEAR PALSY, PROGRESSIVE/ or CORTICOBASAL DEGENERATION/ or LEUKODYSTROPHY, METACHROMATIC/ or exp MITOCHONDRIAL MYOPATHIES/ or exp MUCOPOLYSACCHARIDOSES/ or WILLIAMS SYNDROME/ or GENETIC DISEASES, INBORN/ or RETT SYNDROME/ or FETAL ALCOHOL SPECTRUM DISORDERS/ or DYSTONIC DISORDERS/ or "HEREDITARY SENSORY AND MOTOR NEUROPATHY"/ or SPINAL DYSRAPHISM/

#	Searches
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	MOVEMENT DISORDERS/ or MOTOR DISORDERS/ or CONVERSION DISORDER/
57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	education/ or education, continuing/
64	schools/ or universities/
65	teaching/ or remedial teaching/ or learning/
66	exp students/
67	return to school/
68	education, distance/ or education, professional/ or education, nonprofessional/
69	educational personnel/ or school teachers/ or faculty/ or teacher training/
70	Education, Special/ or Mainstreaming, Education/ or "Education of Intellectually Disabled"/
71	student health services/ or school health services/
72	school nursing/
73	exp training support/
74	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ti.
75	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ab. /freq=2
76	employment/ or unemployment/
77	workplace/ or work/ or occupations/ or workforce/ or work engagement/ or career mobility/
78	vocational education/ or vocational guidance/ or education, professional/
79	Job application/
80	employment, supported/ or sheltered workshops/
81	volunteers/
82	rehabilitation, vocational/
83	return to work/
84	occupational health/ or occupational health services/
85	work performance/ or work schedule tolerance/ or workload/
86	work capacity evaluation/ or "Personnel Staffing and Scheduling"/
87	Working conditions/
88	sick leave/ or pension/ or retirement/
89	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ti.
90	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ab. /freq=2

#	Searches
91	sheltered workshop?.ti,ab.
92	((medical* or disab* or sick*) adj1 (leav* or absen*)).ti,ab.
93	(pension* or retiring or retire*).ti,ab.
94	Social Participation/ or Social Behavior/ or social interaction/ or social skills/ or social group/ or socialization/ or sociological factors/ or social support/ or psychology, social/ or psychosocial functioning/
95	Family/
96	Religion/ or pastoral care/ or spirituality/ or culture/
97	community integration/
98	Leisure Activities/ or recreation/ or hobbies/ or sports/
99	courtship/ or love/
100	Interpersonal Relations/
101	Sex/ or Sex Education/ or Sexual Health/ or sexual behavior/ or orgasm/
102	Contraception Behavior/ or Contraception/
103	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ti.
104	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ab. /freq=2
105	((family or familial or families or parent* or husband* or wife* or wive* or spous* or marriage* or co-habit* or cohabit* or non-marital* or nonmarital* or married or marital or partner* or couple* or sibling* or mother* or father* or sister* or brother* or kinship* or peer? or relative?) adj3 (support* or advis* or advice or group? or engag* or activit* or participat* or interact* or involv*)).ti,ab.
106	or/63-105
107	62 and 106
108	animals/ not humans/
109	exp Animals, Laboratory/
110	exp Animal Experimentation/
111	exp Models, Animal/
112	exp Rodentia/
113	(rat or rats or rodent* or mouse or mice).ti.
114	or/108-113
115	107 not 114
116	limit 115 to english language
117	limit 116 to yr="2010 -Current"
118	qualitative.tw.
119	themes.tw.
120	or/118-119
121	exp United Kingdom/
122	(national health service* or nhs*).ti,ab,in.
123	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
124	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
125	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in.
126	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
127	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.

#	Searches
128	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
129	or/121-128
130	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp australia/ or exp oceania/) not (exp United Kingdom/ or europe/)
131	129 not 130
132	exp Infant/ or Infant Health/ or Infant Welfare/
133	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,jn.
134	exp Child/ or exp Child Behavior/ or Child Health/ or Child Welfare/
135	Minors/
136	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,jn.
137	exp pediatrics/
138	(pediatric* or paediatric* or peadiatric*).ti,ab,in,jn.
139	Adolescent/ or Adolescent Behavior/ or Adolescent Health/
140	Puberty/
141	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,jn.
142	Schools/
143	Child Day Care Centers/ or exp Nurseries/ or Schools, Nursery/
144	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jn.
145	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
146	or/132-145
147	117 and 120 and 131
148	117 and 120 and 146
149	147 or 148

Databases: Embase

Date of last search: 04/08/2023

#	Searches
1	(head injury/ or exp brain injury/ or chronic brain disease/ or brain hemorrhage/ or brain hypoxia/ or exp brain tumor/ or brain disease/ or brain abscess/ or metabolic encephalopathy/ or cerebellum disease/ or exp cerebrovascular disease/ or encephalitis/ or hydrocephalus/) not (exp cerebrovascular accident/ or dementia/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	exp cerebrovascular accident/ and (adolescent/ or "minor (person)"/ or exp child/ or exp infant/ or pediatrics/ or exp pediatrics/ or exp puberty/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	exp spinal cord injury/ or exp spinal cord tumor/ or epidural abscess/ or spinal cord disease/ or exp spinal cord vascular disease/ or spinal cord compression/ or transverse myelitis/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	peripheral nerve injury/ or exp cranial nerve injury/ or peripheral nerve tumor/ or exp cranial nerve tumor/ or exp peripheral neuropathy/ or exp cranial neuropathy/
16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.

#	Searches
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	exp motor neuron disease/ or postpoliomyelitis syndrome/ or exp parkinsonism/ or Duchenne muscular dystrophy/ or exp multiple sclerosis/ or neuromuscular disease/ or hereditary motor sensory neuropathy/ or Friedreich ataxia/ or exp Shy Drager syndrome/ or progressive supranuclear palsy/ or corticobasal degeneration/ or metachromatic leukodystrophy/ or exp mitochondrial myopathy/ or exp mucopolysaccharidosis/ or Williams Beuren syndrome/ or genetic disorder/ or Rett syndrome/ or fetal alcohol syndrome/ or dystonic disorder/ or hereditary motor sensory neuropathy/ or spinal dysraphism/
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	motor dysfunction/ or motor dysfunction/ or conversion disorder/
57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	education/ or academic achievement/ or academic advisement/ or adult education/ or continuing education/ or continuing education provider/ or education program/ or educational mobility/ or primary education/ or secondary education/
64	school/ or college/ or community college/ or high school/ or kindergarten/ or primary school/ or university/
65	teaching/ or learning/
66	exp student/
67	exp return to school/
68	exp distance learning/ or virtual learning environment/ or lifelong learning/
69	exp teacher/ or teacher training/
70	exp special education/ or inclusive education/
71	school health service/ or school mental health service/
72	school health nursing/
73	student assistance program/
74	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ti.
75	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ab. /freq=2
76	exp employment/ or unemployment/
77	workplace/ or work/ or occupation/ or workforce/ or work engagement/ or career/ or career mobility/ or job change/ or vocation/
78	Vocational education/ or vocational guidance/
79	job finding/ or career planning/
80	supported employment/ or sheltered employment/

#	Searches
81	volunteer/ or apprenticeship/
82	Vocational rehabilitation/
83	Return to work/ or work resumption/
84	Occupational health/ or occupational health service/
85	Job performance/ or work schedule/ or workload/ or working time/ or work capacity/
86	personnel management/
87	Job accommodation/ or job adaptation/ or work environment/
88	medical leave/ or pension/ or retirement/
89	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ti.
90	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ab. /freq=2
91	sheltered workshop?.ti,ab.
92	((medical* or disab* or sick*) adj1 (leav* or absen*)).ti,ab.
93	(pension* or retiring or retire*).ti,ab.
94	social behavior/ or social interaction/ or social competence/ or socialization/ or "social aspects and related phenomena"/ or social support/ or social psychology/
95	family/ or family life/ or family functioning/ or family interaction/ or family coping/
96	religion/ or pastoral care/ or spiritual care/ or spiritual well-being/
97	community integration/
98	leisure/ or recreation/ or sport/
99	courtship/ or online dating/ or love/
100	human relation/
101	sex/ or sexual education/ or exp sexual health/ or sexual behavior/ or adolescent sexual behavior/ or sexual practice/ or sexual intercourse/ or orgasm/
102	exp contraceptive behavior/ or contraception/
103	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ti.
104	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ab. /freq=2
105	((family or familial or families or parent* or husband* or wife* or wive* or spous* or marriage* or co-habit* or cohabit* or non-marital* or nonmarital* or married or marital or partner* or couple* or sibling* or mother* or father* or sister* or brother* or kinship* or peer? or relative?) adj3 (support* or advis* or advice or group? or engag* or activit* or participat* or interact* or involv*)).ti,ab.
106	or/63-105
107	62 and 106
108	animal/ not human/
109	nonhuman/
110	exp Animal Experiment/
111	exp Experimental Animal/
112	animal model/
113	exp Rodent/
114	(rat or rats or rodent* or mouse or mice).ti.
115	or/108-114
116	107 not 115
117	limit 116 to english language
118	limit 117 to yr="2010 -Current"
119	qualitative.tw.
120	qualitative study.tw.
121	or/119-120
122	exp United Kingdom/
123	(national health service* or nhs*).ti,ab,in,ad.
124	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
125	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad.
126	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc))

#	Searches
	or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad.
127	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad.
128	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad.
129	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad.
130	or/122-129
131	(exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/) not (exp united kingdom/ or europe/)
132	130 not 131
133	exp juvenile/ or Child Behavior/ or Child Welfare/ or Child Health/ or infant welfare/ or "minor (person)"/ or elementary student/
134	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,ad,jw.
135	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,ad,jw.
136	exp pediatrics/
137	(pediatric* or paediatric* or peadiatric*).ti,ab,in,ad,jw.
138	exp adolescence/ or exp adolescent behavior/ or adolescent health/ or high school student/ or middle school student/
139	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,ad,jw.
140	school/ or high school/ or kindergarten/ or middle school/ or primary school/ or nursery school/ or day care/
141	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jw.
142	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
143	or/133-142
144	118 and 121 and 132
145	118 and 121 and 143
146	or/144-145

Databases: Cochrane Database of Systematic Reviews

Date of last search: 04/08/2023

#	Searches
#1	MeSH descriptor: [Craniocerebral Trauma] this term only
#2	MeSH descriptor: [Brain Injuries] this term only
#3	MeSH descriptor: [Brain Hemorrhage, Traumatic] explode all trees
#4	MeSH descriptor: [Brain Injuries, Diffuse] explode all trees
#5	MeSH descriptor: [Brain Injuries, Traumatic] explode all trees
#6	MeSH descriptor: [Brain Injury, Chronic] explode all trees
#7	MeSH descriptor: [Shaken Baby Syndrome] this term only
#8	MeSH descriptor: [Brain Damage, Chronic] this term only
#9	MeSH descriptor: [Hypoxia, Brain] this term only
#10	MeSH descriptor: [Intracranial Hemorrhage, Traumatic] explode all trees
#11	MeSH descriptor: [Brain Neoplasms] explode all trees
#12	MeSH descriptor: [Brain Diseases] this term only
#13	MeSH descriptor: [Brain Abscess] this term only
#14	MeSH descriptor: [Brain Diseases, Metabolic] this term only
#15	MeSH descriptor: [Cerebellar Diseases] this term only
#16	MeSH descriptor: [Cerebrovascular Disorders] this term only
#17	MeSH descriptor: [Basal Ganglia Cerebrovascular Disease] this term only
#18	MeSH descriptor: [Cerebrovascular Trauma] this term only
#19	MeSH descriptor: [Intracranial Arteriovenous Malformations] this term only
#20	MeSH descriptor: [Intracranial Embolism and Thrombosis] this term only
#21	MeSH descriptor: [Intracranial Hemorrhages] this term only
#22	MeSH descriptor: [Vascular Headaches] this term only
#23	MeSH descriptor: [Encephalitis] this term only
#24	MeSH descriptor: [Hydrocephalus] this term only

#	Searches
#25	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24
#26	MeSH descriptor: [Stroke] explode all trees
#27	MeSH descriptor: [Dementia] this term only
#28	#26 or #27
#29	#25 NOT #28
#30	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) NEAR/2 (injur* or trauma* or damage* or disease* or diseases* or disorder* or infect* or hemorrhag* or haemorrhag* or neoplasm* or cancer* or tumour* or tumor* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)):ti,ab
#31	(chronic* NEAR/1 trauma* NEAR/2 encephalopath*):ti,ab
#32	((infratentorial* or supratentorial* or hypothalam* or pituitar* or "choroid plexus") NEAR/2 (neoplasm* or cancer* or tumour* or tumor* or carcinom* or adenocarcinom*)):ti,ab
#33	(brain* NEAR/2 abscess*):ti,ab
#34	(carotid arter* NEAR/2 (disease* or injur*)):ti,ab
#35	(("basal ganglia" next disease*) or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cerebellar" next degenerat* or "shaken baby" next syndrome* or "shaking baby" next syndrome*):ti,ab
#36	MeSH descriptor: [Stroke] explode all trees
#37	MeSH descriptor: [Adolescent] this term only
#38	MeSH descriptor: [Minors] this term only
#39	MeSH descriptor: [Child] explode all trees
#40	MeSH descriptor: [Infant] explode all trees
#41	MeSH descriptor: [Pediatrics] explode all trees
#42	MeSH descriptor: [Puberty] explode all trees
#43	#37 or #38 or #39 or #40 or #41 or #42
#44	#36 and #43
#45	((stroke or strokes) NEAR/3 (paediatric* or pediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or "under age" or "under ages" or "under aged" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school ages" or "school age" or "school aged" or schoolage* or "under 16" or "under sixteen" or "under sixteens")):ti,ab
#46	MeSH descriptor: [Spinal Cord Injuries] explode all trees
#47	MeSH descriptor: [Spinal Cord Neoplasms] explode all trees
#48	MeSH descriptor: [Epidural Abscess] this term only
#49	MeSH descriptor: [Spinal Cord Diseases] this term only
#50	MeSH descriptor: [Spinal Cord Vascular Diseases] explode all trees
#51	MeSH descriptor: [Spinal Cord Compression] this term only
#52	MeSH descriptor: [Myelitis, Transverse] this term only
#53	((spinal* or spine or spines) NEAR/2 (injur* or trauma* or tumour* or tumor* or neoplasm* or cancer* or infect* or insult* or disease or diseases or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or hemorrhag* or haemorrhag*)):ti,ab
#54	("Central cord" next syndrome* or "transverse myelitis"):ti,ab
#55	(epidural* NEAR/2 (neoplasm* or cancer* or tumour* or tumor* or abscess*)):ti,ab
#56	((spinal* or spine or spines) NEAR/2 (viral* or virus* or polio* or "acquired immunodeficiency syndrome" or AIDS or HIV or bacterial* or neurosyphili* or neuro next syphili* or tubercul*)):ti,ab
#57	MeSH descriptor: [Peripheral Nerve Injuries] this term only
#58	MeSH descriptor: [Cranial Nerve Injuries] explode all trees
#59	MeSH descriptor: [Peripheral Nervous System Neoplasms] this term only
#60	MeSH descriptor: [Cranial Nerve Neoplasms] explode all trees
#61	MeSH descriptor: [Peripheral Nervous System Diseases] explode all trees
#62	MeSH descriptor: [Cranial Nerve Diseases] explode all trees
#63	((periph* or cranial*) NEAR/1 (nerve or nerves or "nervous system") NEAR/2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumour* or tumor* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome*)):ti,ab
#64	(Guillain* NEAR/1 Barr*):ti,ab
#65	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or "ocular motility" or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) NEAR/1 nerve* NEAR/1 injur*):ti,ab
#66	(optic* NEAR/1 nerve* NEAR/2 (neoplasm* or cancer* or tumour* or tumor*)):ti,ab
#67	(brachial next plexus NEAR/1 (neuropath* or neuritis)):ti,ab
#68	("complex regional pain" next syndrome* or causalgia or mononeuropath* or "nerve compression" next syndrome*):ti,ab
#69	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) NEAR/1 neuropath*):ti,ab
#70	((carpal next tunnel or piriformis next muscle or tarsal next tunnel or thoracic next outlet) NEAR/1 syndrome*):ti,ab
#71	((pudendal next neuralgia) or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*):ti,ab
#72	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or "ocular motility" or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) NEAR/1 nerve* NEAR/1 disease*):ti,ab
#73	(periph* NEAR/2 neuropath*):ti,ab
#74	(((periph* or cranial*) NEAR/2 (nerve or nerves or "nervous system")) and lupus):ti,ab
#75	((multi next focal* or multifocal*) NEAR/2 motor NEAR/1 neuropath*):ti,ab
#76	(((periph* or cranial*) NEAR/2 (nerve or nerves or nervous system)) and alcohol*):ti,ab

#	Searches
#77	#29 or #30 or #31 or #32 or #33 or #34 or #35 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or #73 or #74 or #75 or #76
#78	MeSH descriptor: [Motor Neuron Disease] explode all trees
#79	MeSH descriptor: [Postpoliomyelitis Syndrome] this term only
#80	MeSH descriptor: [Parkinsonian Disorders] explode all trees
#81	MeSH descriptor: [Muscular Dystrophy, Duchenne] this term only
#82	MeSH descriptor: [Multiple Sclerosis] explode all trees
#83	MeSH descriptor: [Neuromuscular Diseases] this term only
#84	MeSH descriptor: [Spastic Paraplegia, Hereditary] this term only
#85	MeSH descriptor: [Friedreich Ataxia] this term only
#86	MeSH descriptor: [Multiple System Atrophy] explode all trees
#87	MeSH descriptor: [Supranuclear Palsy, Progressive] this term only
#88	MeSH descriptor: [Corticobasal Degeneration] explode all trees
#89	MeSH descriptor: [Leukodystrophy, Metachromatic] this term only
#90	MeSH descriptor: [Mitochondrial Myopathies] explode all trees
#91	MeSH descriptor: [Mucopolysaccharidoses] explode all trees
#92	MeSH descriptor: [Williams Syndrome] this term only
#93	MeSH descriptor: [Genetic Diseases, Inborn] this term only
#94	MeSH descriptor: [Rett Syndrome] this term only
#95	MeSH descriptor: [Fetal Alcohol Spectrum Disorders] this term only
#96	MeSH descriptor: [Dystonic Disorders] this term only
#97	MeSH descriptor: [Hereditary Sensory and Motor Neuropathy] this term only
#98	MeSH descriptor: [Spinal Dysraphism] this term only
#99	(neurolog* NEAR/1 (condition* or disease* or damage* or disorder* or impair*)):ti,ab
#100	((motor next neuron* or gehrig* or charcott* or kennedy*) NEAR/1 disease*):ti,ab
#101	((amyotroph* or primary) NEAR/1 lateral* NEAR/1 sclero*):ti,ab
#102	(bulbar NEAR/1 pals*):ti,ab
#103	((muscular or muscle* or bulbo) NEAR/1 atroph* NEAR/1 spin*):ti,ab
#104	(progressiv* NEAR/1 (muscular or muscle*) NEAR/1 atroph*):ti,ab
#105	((postpolio* or post next polio*) NEAR/1 (syndrome*)):ti,ab
#106	(Parkinson* or duchenne* or multiple next scleros* or sclerosos* or aphasia or creutzfeldt next jakob or huntington* or kluver next bucy):ti,ab
#107	(muscular NEAR/1 dystroph*):ti,ab
#108	(neuromusc* adj1 (disease* or disorder?)):ti,ab
#109	(heredit* NEAR/1 spastic* NEAR/1 parapleg*):ti,ab
#110	(friedreich* next ataxia*):ti,ab
#111	(("multiple system" or olivopontocerebellar) NEAR/1 atroph*):ti,ab
#112	((shy next drager next syndrome*) or striatonigral next degenerat* or batten next disease*):ti,ab
#113	(progressive NEAR/1 supranuclear NEAR/1 pals*):ti,ab
#114	(richardson* NEAR/1 (disease* or syndrome*)):ti,ab
#115	((corticobasal or "cortico basal") NEAR/1 degenerat*):ti,ab
#116	("white matter" NEAR/1 (disorder*)):ti,ab
#117	(metachromatic next leukodystroph* or mitochondrial next myopath* or mucopolysaccharidos*):ti,ab
#118	(lysosomal NEAR/1 storage NEAR/1 disorder*):ti,ab
#119	((genetic or William* or "catch-22" or rett* or congenital or fetal or "foetal alcohol") NEAR/1 (syndrome* or disorder*)):ti,ab
#120	(perinatal NEAR/1 (illness* or hypoxia*)):ti,ab
#121	(primary NEAR/1 (dystonia or dystonias)):ti,ab
#122	(heredit* NEAR/1 motor* NEAR/1 sens* NEAR/1 neuropath*):ti,ab
#123	(spina next (bifida or bifidas) or spinal next (dysraphism or dysraphisms)):ti,ab
#124	MeSH descriptor: [Movement Disorders] this term only
#125	MeSH descriptor: [Motor Disorders] this term only
#126	MeSH descriptor: [Conversion Disorder] this term only
#127	((functional* or psychogenic* or dissociative*) NEAR/1 neurologic* NEAR/1 (disorder* or dysfunction* or difficult*)):ti,ab
#128	((movement* or motor* or convers*) NEAR/1 (disorder* or dysfunct*)):ti,ab
#129	((psychogenic or dissociative or non-epilep* or nonepilep*) NEAR/1 (seizure* or convulsion* or fit or fits or spasm* or attack*)):ti,ab
#130	(pseudo next seizure or pseudoseizure):ti,ab
#131	(medical* NEAR/1 (unexplain* or un next explain*) NEAR/1 (symptom*)):ti,ab
#132	#77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108 or #109 or #110 or #111 or #112 or #113 or #114 or #115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124 or #125 or #126 or #127 or #128 or #129 or #130 or #131
#133	MeSH descriptor: [Education] this term only
#134	MeSH descriptor: [Education, Continuing] this term only
#135	MeSH descriptor: [Schools] this term only
#136	MeSH descriptor: [Universities] this term only

#	Searches
#137	MeSH descriptor: [Teaching] this term only
#138	MeSH descriptor: [Remedial Teaching] this term only
#139	MeSH descriptor: [Learning] this term only
#140	MeSH descriptor: [Students] explode all trees
#141	MeSH descriptor: [Return to School] this term only
#142	MeSH descriptor: [Education, Distance] this term only
#143	MeSH descriptor: [Education, Professional] this term only
#144	MeSH descriptor: [Education, Nonprofessional] this term only
#145	MeSH descriptor: [Educational Personnel] this term only
#146	MeSH descriptor: [School Teachers] this term only
#147	MeSH descriptor: [Faculty] this term only
#148	MeSH descriptor: [Teacher Training] this term only
#149	MeSH descriptor: [Education, Special] this term only
#150	MeSH descriptor: [Mainstreaming, Education] this term only
#151	MeSH descriptor: [Education of Intellectually Disabled] this term only
#152	MeSH descriptor: [Student Health Services] this term only
#153	MeSH descriptor: [School Health Services] this term only
#154	MeSH descriptor: [School Nursing] this term only
#155	MeSH descriptor: [Training Support] explode all trees
#156	(educat* or school* or universit* or college* or academ* or classroom* or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor* or lecturer* or facult* or professor* or graduat* or postgrad* or student* or pupil* or undergrad* or campus*):ti
#157	(educat* or school* or universit* or college* or academ* or classroom* or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor* or lecturer* or facult* or professor* or graduat* or postgrad* or student* or pupil* or undergrad* or campus*):ab
#158	MeSH descriptor: [Employment] this term only
#159	MeSH descriptor: [Unemployment] this term only
#160	MeSH descriptor: [Workplace] this term only
#161	MeSH descriptor: [Work] this term only
#162	MeSH descriptor: [Occupations] this term only
#163	MeSH descriptor: [Workforce] this term only
#164	MeSH descriptor: [Work Engagement] this term only
#165	MeSH descriptor: [Career Mobility] this term only
#166	MeSH descriptor: [Vocational Education] this term only
#167	MeSH descriptor: [Vocational Guidance] this term only
#168	MeSH descriptor: [Education, Professional] this term only
#169	MeSH descriptor: [Job Application] this term only
#170	MeSH descriptor: [Employment, Supported] this term only
#171	MeSH descriptor: [Sheltered Workshops] this term only
#172	MeSH descriptor: [Volunteers] this term only
#173	MeSH descriptor: [Rehabilitation, Vocational] this term only
#174	MeSH descriptor: [Vocational Education] this term only
#175	MeSH descriptor: [Vocational Guidance] this term only
#176	MeSH descriptor: [Return to Work] this term only
#177	MeSH descriptor: [Occupational Health] this term only
#178	MeSH descriptor: [Occupational Health Services] this term only
#179	MeSH descriptor: [Work Performance] this term only
#180	MeSH descriptor: [Work Schedule Tolerance] this term only
#181	MeSH descriptor: [Workload] this term only
#182	MeSH descriptor: [Work Capacity Evaluation] this term only
#183	MeSH descriptor: [Personnel Staffing and Scheduling] this term only
#184	MeSH descriptor: [Working Conditions] this term only
#185	MeSH descriptor: [Sick Leave] this term only
#186	MeSH descriptor: [Pensions] this term only
#187	MeSH descriptor: [Retirement] this term only
#188	(career* or job* or work* or employ* or unemploy* or vocation* or prevocation* or (labor next market*) or (labour next market*) or occupation* or profession* or intern or interns or internship* or trainee* or apprentice* or volunteer* or (human next resource*) or HR):ti
#189	(career* or job* or work* or employ* or unemploy* or vocation* or prevocation* or (labor next market*) or (labour next market*) or occupation* or profession* or intern or interns or internship* or trainee* or apprentice* or volunteer* or (human next resource*) or HR):ab
#190	sheltered next workshop*:ti,ab
#191	((medical* or disab* or sick*) near/1 (leav* or absen*)):ti,ab
#192	(pension* or retiring or retire*):ti,ab
#193	MeSH descriptor: [Social Participation] this term only
#194	MeSH descriptor: [Social Behavior] this term only
#195	MeSH descriptor: [Social Interaction] this term only
#196	MeSH descriptor: [Social Skills] this term only
#197	MeSH descriptor: [Social Group] this term only

#	Searches
#198	MeSH descriptor: [Socialization] this term only
#199	MeSH descriptor: [Sociological Factors] this term only
#200	MeSH descriptor: [Social Support] this term only
#201	MeSH descriptor: [Psychology, Social] this term only
#202	MeSH descriptor: [Psychosocial Functioning] this term only
#203	MeSH descriptor: [Family] this term only
#204	MeSH descriptor: [Religion] this term only
#205	MeSH descriptor: [Pastoral Care] this term only
#206	MeSH descriptor: [Spirituality] this term only
#207	MeSH descriptor: [Culture] this term only
#208	MeSH descriptor: [Community Integration] this term only
#209	MeSH descriptor: [Leisure Activities] this term only
#210	MeSH descriptor: [Recreation] this term only
#211	MeSH descriptor: [Hobbies] this term only
#212	MeSH descriptor: [Sports] this term only
#213	MeSH descriptor: [Courtship] this term only
#214	MeSH descriptor: [Love] this term only
#215	MeSH descriptor: [Interpersonal Relations] this term only
#216	MeSH descriptor: [Sex] this term only
#217	MeSH descriptor: [Sex Education] this term only
#218	MeSH descriptor: [Sexual Health] this term only
#219	MeSH descriptor: [Sexual Behavior] this term only
#220	MeSH descriptor: [Orgasm] this term only
#221	MeSH descriptor: [Contraception Behavior] this term only
#222	MeSH descriptor: [Contraception] this term only
#223	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle* or shop* or money* or budget* or finance* or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club or clubs or network* or forum* or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship* or relationship* or interpersonal or (inter next personal) or sex* or erection* or erectile or orgasm* or contracepti*):ti
#224	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle* or shop* or money* or budget* or finance* or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club or clubs or network* or forum* or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship* or relationship* or interpersonal or (inter next personal) or sex* or erection* or erectile or orgasm* or contracepti*):ab
#225	((family or familial or families or parent* or husband* or wife* or wive* or spous* or marriage* or (co next habit*) or cohabit* or (non next marital*) or nonmarital* or married or marital or partner* or couple* or sibling* or mother* or father* or sister* or brother* or kinship* or peer* or relative*) near/3 (support* or advis* or advice or group* or engag* or activit* or participat* or interact* or involv*)):ti,ab
#226	#133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146 or #147 or #148 or #149 or #150 or #151 or #152 or #153 or #154 or #155 or #156 or #157 or #158 or #159 or #160 or #161 or #162 or #163 or #164 or #165 or #166 or #167 or #168 or #169 or #170 or #171 or #172 or #173 or #174 or #175 or #176 or #177 or #178 or #179 or #180 or #181 or #182 or #183 or #184 or #185 or #186 or #187 or #188 or #189 or #190 or #191 or #192 or #193 or #194 or #195 or #196 or #197 or #198 or #199 or #200 or #201 or #202 or #203 or #204 or #205 or #206 or #207 or #208 or #209 or #210 or #211 or #212 or #213 or #214 or #215 or #216 or #217 or #218 or #219 or #220 or #221 or #222 or #223 or #224 or #225
#227	#132 and #226
#228	qualitative:ti,ab
#229	themes:ti,ab
#230	#228 or #229
#231	#227 and #230
#232	#227 and #230 with Cochrane Library publication date Between Jan 2010 and Aug 2023, in Cochrane Reviews

Database: Social Policy and Practice

Date of last search: 04/08/2023

#	Searches
1	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or infarcti* or hypoxi* or drown*)).ti,ab.
2	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
3	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
4	(brain* adj2 abscess*).ti,ab.
5	(carotid arter* adj2 (disease* or injur*)).ti,ab.
6	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
7	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.

#	Searches
8	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
9	(Central cord syndrome* or transverse myelitis).ti,ab.
10	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
11	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
12	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
13	(Guillain* adj1 Barr*).ti,ab.
14	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
15	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
16	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
17	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
18	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
19	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
20	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
21	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
22	(periph* adj2 neuropath*).ti,ab.
23	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
24	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
25	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
26	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
27	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
28	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
29	(bulbar adj1 pals*).ti,ab.
30	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
31	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
32	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
33	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
34	(muscular adj1 dystroph*).ti,ab.
35	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
36	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
37	"friedreich* ataxia*".ti,ab.
38	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
39	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
40	(progressive adj1 supranuclear adj1 pals*).ti,ab.
41	(richardson* adj1 (disease? or syndrome?)).ti,ab.
42	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
43	(white adj1 matter adj1 disorder?).ti,ab.
44	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
45	(lysosomal adj1 storage adj1 disorder?).ti,ab.
46	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
47	(perinatal illness* or perinatal hypoxia*).ti,ab.
48	(primary adj1 dystonia?).ti,ab.
49	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
50	(spina bifida? or spinal dysraphism?).ti,ab.
51	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
52	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
53	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
54	(pseudo-seizure* or pseudoseizure*).ti,ab.
55	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
56	or/1-55
57	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ti.
58	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ab. /freq=2
59	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ti.
60	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ab. /freq=2
61	sheltered workshop?.ti,ab.
62	((medical* or disab* or sick*) adj1 (leav* or absen*)).ti,ab.
63	(pension* or retiring or retire*).ti,ab.

#	Searches
64	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ti.
65	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ab. /freq=2
66	((family or familial or families or parent* or husband* or wife* or wive* or spous* or marriage* or co-habit* or cohabit* or non-marital* or nonmarital* or married or marital or partner* or couple* or sibling* or mother* or father* or sister* or brother* or kinship* or peer? or relative?) adj3 (support* or advis* or advice or group? or engag* or activit* or participat* or interact* or involv*)).ti,ab.
67	or/57-66
68	56 and 67
69	limit 68 to yr="2010 -Current"
70	interview*.ti,ab.
71	experience*.ti,ab.
72	qualitative*.ti,ab.
73	theme?.ti,ab.
74	view?.ti,ab.
75	survey*.ti,ab.
76	focus group?.ti,ab.
77	or/70-76
78	69 and 77

Database: PsycInfo

Date of last search: 04/08/2023

#	Searches
1	(exp Brain Injuries/ or anoxia/ or exp brain disorders/ or exp cerebrovascular disorders/ or exp headache/) not (exp Dementia/ or Cerebrovascular Accidents/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	Cerebrovascular Accidents/ and (exp childhood development/ or exp adolescent development/ or pediatrics/ or puberty/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	spinal cord injuries/ or (Spinal Cord/ and neoplasms/) or (Cardiovascular Disorders/ and spinal cord/) or exp myelitis/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	(exp Peripheral Nervous System/ and (Injuries/ or neoplasms/)) or nervous system disorders/
16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.

#	Searches
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	motor neurons/ or exp muscular disorders/ or exp neuromuscular disorders/ or multiple sclerosis/ or neurodegenerative diseases/ or Progressive Supranuclear Palsy/ or corticobasal degeneration/ or Metabolism Disorders/ or Williams Syndrome/ or genetic disorders/ or rett syndrome/ or fetal alcohol syndrome/ or exp peripheral neuropathy/ or spina bifida/
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	conversion disorder/
57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	education/ or exp adult education/ or educational degrees/ or educational placement/ or elementary education/ or high school education/ or exp higher education/ or middle school education/ or paraprofessional education/ or private school education/ or public school education/ or secondary education/ or remedial education/ or compensatory education/ or exp nontraditional education/
64	exp academic settings/ or school attendance/ or school enrollment/ or exp school transition/ or school adjustment/
65	teaching/ or tutoring/ or learning/ or adult learning/ or school learning/
66	exp Students/
67	distance education/ or blended learning/ or exp electronic learning/ or virtual classrooms/
68	educational personnel/ or school administrators/ or school counselors/ or teacher aides/ or exp teachers/
69	teacher education/ or teaching methods/
70	exp Special Education/ or special needs/ or individualized instruction/
71	college mental health services/ or school based mental health services/ or student personnel services/
72	school nurses/
73	school facilities/ or academic environment/ or classroom environment/ or exp school environment/ or learning environment/
74	educational programs/
75	training/ or personnel training/ or coaching/ or coaches/ or mentor/
76	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ti.
77	(educat* or school* or universit* or college? or academ* or classroom? or train* or learn* or elearning or "e learning" or curricul* or teach* or tutor? or lecturer? or facult* or professor? or graduat* or postgrad* or student? or pupil? or undergrad* or campus?).ab. /freq=2
78	exp employment status/
79	exp occupations/ or career change/ or occupational choice/ or occupational mobility/ or reemployment/ or employee engagement/ or job search/
80	exp vocational education/ or occupational guidance/ or vocational counselors/ or career education/ or career development/ or professional development/ or professional certification/
81	training/ or personnel training/ or job applicants/ or coaching/ or coaches/ or mentor/ or occupational aspirations/
82	exp Sheltered Workshops/ or exp Supported Employment/

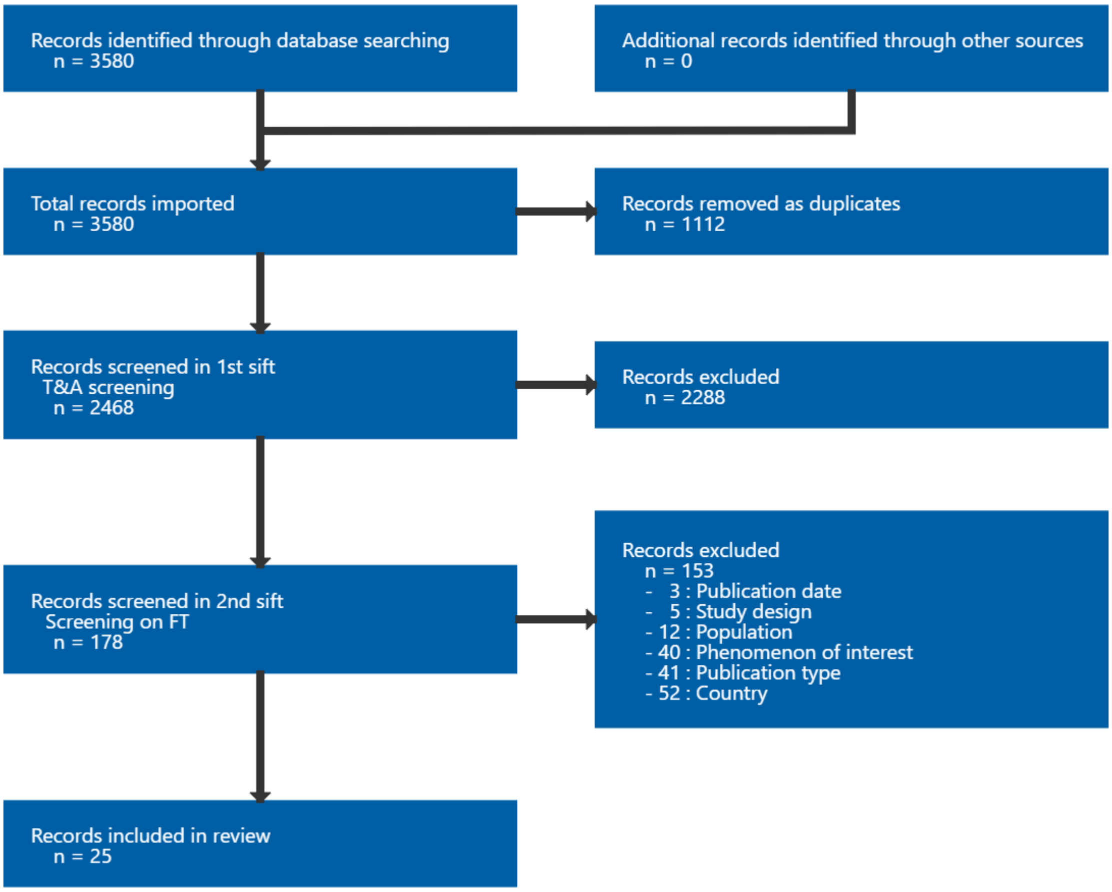
#	Searches
83	apprenticeship/ or *volunteers/
84	vocational rehabilitation/ or vocational evaluation/ or workplace intervention/ or exp disability management/ or employee retention/
85	occupational health/ or occupational adjustment/ or work adjustment training/
86	exp job performance/ or exp working conditions/ or employee assistance programs/
87	employee leave benefits/ or exp employee health insurance/ or employee pension plans/ or disability evaluation/ or exp government programs/ or retirement/
88	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ti.
89	(career? or job? or work* or employ* or unemploy* or vocation* or prevocation* or labo?r market? or occupation* or profession* or intern? or internship? or trainee? or traineeship? or apprentice* or volunteer* or human resource? or HR).ab. /freq=2
90	sheltered workshop?.ti,ab.
91	((medical* or disab* or sick*) adj1 (leav* or absen*)).ti,ab.
92	(pension* or retiring or retire*).ti,ab.
93	Social Behavior/ or Social Interaction/ or social skills/ or social communication/ or social functioning/ or socioemotional functioning/ or social groups/ or socialization/ or social processes/ or sociocultural factors/ or psychosocial factors/ or social support/ or perceived social support/ or social networks/ or social resources/ or support groups/ or online social networks/
94	Family/ or Marital Relations/ or significant others/
95	Religion/ or Pastoral Counseling/ or Spirituality/
96	Community Involvement/ or community integration/
97	Recreation/ or Leisure Time/ or interests/ or hobbies/ or Adaptive Sports/ or Sports/
98	Human Courtship/ or Love/
99	Interpersonal Interaction/ or Interpersonal Relationships/
100	Sex/ or Sex Education/ or psychosexual behavior/ or sexual health/ or "sexual intercourse (human)"/ or orgasm/ or Sexual Satisfaction/
101	birth control/
102	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ti.
103	(social* or friend* or befriend* or religio* or spiritual* or pastoral* or faith or cultur* or communit* or drive or driving or transport* or car or cars or vehicle? or shop* or money* or budget* or finance? or financial* or income* or activit* or leisure* or hobby or hobbies or pastime* or club? or network* or forum? or sport* or exercis* or fitness or cultural* or recreation* or romantic* or romance or dating or love or courtship? or relationship? or inter?personal or sex* or erection? or erectile or orgasm* or contracepti*).ab. /freq=2
104	((family or familial or families or parent* or husband* or wife* or wive* or spous* or marriage* or co-habit* or cohabit* or non-marital* or nonmarital* or married or marital or partner* or couple* or sibling* or mother* or father* or sister* or brother* or kinship* or peer? or relative?) adj3 (support* or advis* or advice or group? or engag* or activit* or participat* or interact* or involv*)).ti,ab.
105	or/63-104
106	62 and 105
107	animal.po.
108	(rat or rats or mouse or mice or rodent*).ti.
109	or/107-108
110	106 not 109
111	limit 110 to english language
112	limit 111 to yr="2010 -Current"
113	qualitative:.tw.
114	themes.tw.
115	or/113-114
116	(national health service* or nhs*).ti,ab,in,cq.
117	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
118	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq.
119	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or

#	Searches
	portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,cq.
120	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,cq.
121	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,cq.
122	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,cq.
123	or/116-122
124	(adolescence 13 17 yrs or childhood birth 12 yrs or infancy 2 23 mo or neonatal birth 1 mo or preschool age 2 5 yrs or school age 6 12 yrs).ag.
125	Pediatrics/ or Puberty/ or Adolescence/
126	(child* or adolescen* or baby or babies or boy? or girl? or infan* or juvenile? or kid? or kindergar* or minors or neonat* or newborn? or p?ediatric* or prepubert* or pre pubert* or prepubescen* or pre pubescen* or preschool* or pre school* or preteen* or pre teen* or pubert* or pubescen* or schoolchild* or school age? or teen* or toddler* or young or youth?).ti,ab.
127	(child* or adolescen* or baby or babies or infan* or juvenile? or kindergar* or neonat* or newborn? or p?ediatric* or prepubert* or pre pubert* or pubert* or schoolchild* or school age?).jw.
128	or/124-127
129	112 and 115 and 123
130	112 and 115 and 128
131	or/129-130

Appendix C Qualitative evidence study selection

Study selection for: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

Figure 3: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

Table 4: Evidence tables

Abbott, 2014

Bibliographic Reference	Abbott, David; Carpenter, John; 'Wasting precious time': young men with Duchenne muscular dystrophy negotiate the transition to adulthood; Disability and Society; 2014; vol. 29 (no. 8); 1192-1205

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community. Three English regions containing a mixture of urban and rural settings with varied socio-economic profiles. **Aim** To explore the experiences of young men with Duchenne muscular dystrophy and their families when transitioning to adulthood (including from children's to adults' services and from education to employment).
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted 1.5-3.5 hours, with an average of approximately 2 hours. Location: Not reported

	Format: Face-to-face, recorded and transcribed. Young men were offered the choice of attending interviews on their own or with other family members. Twelve participated alone and 25 with family members. In some cases, young men started with family members in attendance before completing the interview alone. **Analysis** Thematic content analysis. MAXQDA qualitative software was used, with a constant comparative method of analysis to test emerging hypotheses. Particular attention was paid to deviant cases, to prevent researchers treating experiences of young men and family members as being the same. To check for accuracy and consistency in the analysis, 2 researchers exchanged transcripts following initial coding. Team meetings were used to discuss and generate hypotheses.
Recruitment strategy	Doctors specialising in Duchenne muscular dystrophy from regional paediatric and adult NHS services invited all eligible young men and families from their databases to participate.
Study dates	2008-2010
Sources of funding	Not industry funded
Inclusion criteria	• Families with a son with Duchenne muscular dystrophy aged 15 years or above.
Exclusion criteria	Not reported
Sample size	N=95 young men with Duchenne muscular dystrophy plus parents and siblings
Participant characteristics	**Young men with Duchenne muscular dystrophy, n=37** Age in years [Mean (SD)]: 19.6 (SD not reported), age range 15-33 Sex (M/F): n=37/n=0 Time since diagnosis in years: Not reported Chronic neurological disorder category: Progressive neurological disease **Parents and siblings of young men with Duchenne muscular dystrophy, n=58** Age of people with chronic neurological disorders in years [Mean (SD)]: As above

	Sex of people with chronic neurological disorders (M/F): As above
Results	Themes as described in paper: • Activities and support at transition ○ Young men with Duchenne's reported not being aware of alternatives to education, and therefore were still attending college as a default rather than a choice. Professionals meant to assist with finding work took a negative view on a person's abilities, which prevented options and alternatives being discussed. One participant who had experience of paid employment had been assigned a job coach through his college, who worked with him to find practical solutions for his barriers to employment. ○ Young men with Duchenne's muscular dystrophy reported not knowing what social activities were available to them, which limited their participation. ○ *“I made an appointment to see the Disability Employment Advisor at the job centre, but she wasn’t much good to be honest. She pretty much said straight away that there wouldn’t be any work that I’d be able to do. I was hoping for a bit more of a positive approach than that!” (page 1197)* ○ *"I go out with my mum for my dinner on a Tuesday. Sometimes I go to bingo. That’s about it. We don’t know what else there is out there for us." (page 1197)* • Complex and shifting transitions ○ Respondents reported that the life-limiting aspect of Duchenne's meant that families were reluctant to place added pressure on people with Duchenne’s and were therefore selective about what information they shared and how much they supported them to find employment options for them. ○ *“He sees school as somewhere to do social events rather than learn. He’s very much of the view that he’s never going to get a job, ‘Cos I’m too physically disabled’, and I have to agree with him.” (page 1198)* • Shorter lives as less valuable? ○ Respondents felt as though support services were less likely to offer help for people with life-limiting conditions because they were seen to be a difficult population. This ambivalence was exacerbated by views that the young men would receive government benefits either way, so employment was not paramount.

	○ *"It does seem to be that before you're 16 there is a plan – this happens, then that happens, and it's smooth. Then you get to a certain age and no-one's thought about what happens next. It's like, 'We've done our job now, it doesn't really matter what happens next.' Once you've done with school it's like, 'OK, well you've got your benefits you can sit at home and do nothing and that's fine'." (page 1200)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of recruitment and data analysis, lack of discussion regarding credibility, lack of discussion about study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Abbott, 2016

Bibliographic Reference	Abbott, David; Jepson, Marcus; Hastie, Jon; Men living with long-term conditions: exploring gender and improving social care.; Health & social care in the community; 2016; vol. 24 (no. 4); 420-7

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK

Setting and aim	**Setting** In the community **Aim** To explore the experiences of young men with Duchenne muscular dystrophy with the delivery of social care and its impact on male identity.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted 65 minutes on average (range 36-106 minutes). Location: Participant's homes. Format: Face-to-face, digitally recorded and fully transcribed. Interview schedule was drafted following a review of the literature and piloted with 2 young men with Duchenne muscular dystrophy. Analysis was performed and changes made for subsequent interviews in light of results. **Analysis** Thematic analysis. Transcripts were exchanged between 3 researchers to ensure consistency. Emerging themes and sub-themes were discussed in person, and broad headings agreed. Additionally, a 2-day analysis meeting with national and international experts was held, where experts looked at half of the transcripts and offered interpretations based on their personal area of expertise.
Recruitment strategy	Participants were recruited from the Duchenne Family Support Group, using Facebook pages related to muscular dystrophy. Interested respondents were sent information about the study, along with a copy of the interview topic guide.
Study dates	2013
Sources of funding	Not industry funded
Inclusion criteria	Not reported
Exclusion criteria	Not reported

Sample size	N=20 young men with Duchenne muscular dystrophy
Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 21-33 Sex (M/F): n=20/n=0 Time since diagnosis in years: Not reported Chronical neurological disorder category: Progressive neurological disease.
Results	Themes as described in paper: • Organising and delivering social care support ○ Respondents reported that discussions around intimate and sexual relationships (including the physical and emotional challenges that might accompany them) were seldom discussed in assessment, planning and review of rehabilitation. Similarly, discussions about how a lack of access to funding and staff can negatively affect access to social interactions and community participation (and how this might affect an individual's sense of masculinity) were not had. This is despite most respondents reporting that they would be open to these discussions in assessment and support planning appointments. ○ Opportunities to go outside were limited in the respondents that reported they did not receive enough hours of support. This would not only affect their ability to be outside the home, but could also affect opportunities to take risk, avoid parental oversight, and develop romantic relationships. Additionally, if support workers were not available to drive, young men with Duchenne's were unlikely to leave the house at all. ○ *“No, they don’t ask those kinds of questions. Open, yeah. I would have been very open. But they might feel embarrassed. But me, I’m kind of an open guy, so it’s just natural, really.” (page 424)* • Sex, body and intimacy ○ Respondents reflected that they often had practical issues with masturbation, which was frustrating. However, they were too embarrassed to bring the topic up with care professionals and only 1 reported that a care professional had done so. The majority reported that they would be open to these discussions. However, respondents wanted a cue of when to initiate these discussions about sex and relationships. They said it is not an easy conversation to start as it frequently seems to be outside the 'normal' agenda in rehabilitation planning, assessment or review meetings. Having healthcare professionals be more open to the topic would help this.

	○ *"Participant: . . .it would be good in general, in the care industry, if they thought about these things more. Things about sex, which are important to people. Relationship things. It might be just me, and if I did talk about it, it would be fine. But it has to come from both you and the agencies. It would be valuable. It's quite an important part about being. . . But it's not something they obviously think about at all. If they were more open about it, it might be easier for me to talk to my carers about. Interviewer: So it's never, for example, featured in those planning discussions or. . . Participant: No. Not really, no. It might make it easier to be open about it if they were." (page 425)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of recruitment, data collection and data analysis, lack of discussion regarding credibility.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Barrett, 2022

Bibliographic Reference	Barrett, Olivia E C; Ho, Aileen K; Finlay, Katherine A; Supporting Sexual Functioning and Satisfaction During Rehabilitation after Spinal Cord Injury: Barriers and Facilitators Identified by Healthcare Professionals.; Journal of rehabilitation medicine; 2022; vol. 54; jrm00298

Study Characteristics

Study type	General qualitative inquiry

Country/ies where study was carried out	UK
Setting and aim	**Setting** Spinal cord injury case management organisation **Aim** To explore healthcare professionals' experiences and views on the barriers and facilitators to accessing support for sexual functioning and wellbeing after spinal cord injury.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted on average 77.5 minutes (range 35-115 minutes). Location: Not reported Format: Face-to-face (n=5) and video conference (n=11), audio recorded, and transcribed. Nine-item interview schedule was developed using previous interviews with people with spinal cord injury and a review of the literature. **Analysis** Thematic analysis. Transcripts were read multiple times before generating initial codes on barriers and facilitators, that were then condensed down into themes. These initial themes were then reviewed and finalised. Data saturation was pre-determined at 3 (no further explanation given). Inter-rater reliability analysis was performed and calculated to be 91.3%. Any disagreements were resolved through discussion within the research team and referral back to original transcripts.
Recruitment strategy	Purposive sampling. Participants were recruited through a private case management company specialising in spinal cord injury care. Interested respondents were sent information on the study via email. Consent forms and demographic questionnaires were completed and returned before interviews commenced.
Study dates	Not reported
Sources of funding	Not industry funded

Inclusion criteria	• Healthcare professionals over 18 years old currently working with people with spinal cord injury and proficient in spoken English.
Exclusion criteria	• Healthcare professionals not employed in specialist inpatient or outpatient spinal cord injury settings.
Sample size	N=16 healthcare professionals working with people with spinal cord injury
Participant characteristics	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=4 case managers, n=3 nurses, n=3 physiotherapists, n=2 occupational therapists, n=2 psychologists, n=2 psychosexual therapists Chronical neurological disorder category: Acquired spinal cord injury
Results	Themes as described in paper: • Integrating sexual wellbeing in rehabilitation ○ Respondents felt as though including sexual function and personal relationships within standardised assessments could ensure that the topic of sexual functioning and satisfaction is not overlooked in rehabilitation. Healthcare professionals said that this topic should be included from the beginning of rehabilitation, to help it fit more naturally in assessments. This inclusion would help to normalise the subject and allow it to integrate better with standard care and other rehabilitation services. ○ *“I think it needs to become a standardized assessment or discussion like everything else, like are you able to wash and dress? Can you get off the floor if you fall out of your wheelchair? These are the types of regular discussions we have with clients. I don’t think we have discussions about sexual function, but we should. It should be standardized across the board.” (page 4)* • Sex-informed MDTs ○ Respondents noted that limited knowledge and support were barriers to accessing sexual rehabilitation services. Lack of training and support for healthcare professionals was seen to compound this.

	○ *“I suppose it is hard for us sometimes because there isn’t much on offer for us either in terms of education and training and I think it just adds to the problem” (page 5)* • Acknowledging awkwardness ○ Healthcare professionals noted that their own reservations and cultural attitudes to sexual functioning and satisfaction could act as a barrier to starting discussions. This reticence about having conversations about sexual wellbeing also meant that the topic was not referenced in care delivery notes and therefore in subsequent rehabilitation. ○ *“I have, in the past, asked clients about it and have begun to type it into a report based on client’s needs, but then I have found myself deleting it before sending the report across to the legal teams because you do have that little niggle and worry that somehow you shouldn’t be including this or maybe it’s not the right time and I suppose it is not knowing how others will react when reading that.” (page 5)* • Enhancing MDT approachability ○ Participants reported that involving individuals in conversations about sexual wellbeing allows people with spinal cord injury the opportunity to consider their sexual functioning and satisfaction. The difference in the large amount of information available for non-sexual and the absence of information on sexual rehabilitation was highlighted. This lack of available information was seen to further decrease approachability for people with spinal cord, creating an additional barrier to accessing services. Conversely, providing this information could increase approachability and encourage people with spinal cord injury to reflect on their sexual wellbeing and rehabilitation needs. ○ *“Being open and being able to talk about this is not possible for a lot of people, so with the PLISSIT model, Permission, [Limited] Information, Specific Suggestions [and Intensive Therapy], so having posters up all over your spinal unit, having information available through charities and things like that.” (page 5)*

MDT: multidisciplinary team; N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment and data collection methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Barrett, 2023

Bibliographic Reference	Barrett, Olivia E C; Mattacola, Emily; Finlay, Katherine A; "You feel a bit unsexy sometimes": The psychosocial impact of a spinal cord injury on sexual function and sexual satisfaction.; Spinal cord; 2023; vol. 61 (no. 1); 51-56

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community **Aim** To explore the views of people with spinal cord injury on psychosocial barriers and facilitators to sexual functioning and wellbeing after injury.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted on average 65.15 minutes (range 30-120 minutes).

	Location: Not reported Format: Face-to-face (n=4) and video conference (n=16), audio recorded, and transcribed. Eight-item interview schedule was developed using previous interviews with people with spinal cord injury and a review of the literature. **Analysis** Thematic analysis. Transcripts were read multiple times before generating initial codes on barriers and facilitators, that were then condensed into themes. These initial themes were then reviewed and finalised. Data saturation was pre-determined at 3 (no further explanation given). Inter-rater reliability analysis performed and calculated to be 91%. Any disagreements were resolved through discussion within the research team and referral back to original transcripts and field notes.
Recruitment strategy	Purposive sampling. Participants meeting inclusion criteria were recruited from private case management company specialising in spinal cord injury care, and invited to participate via email along with information on the study.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	• People over 18 years old with a diagnosis of spinal cord injury, living in the community for over 18 months, and with a spoken proficiency in English. ○ Spinal cord injury as defined by the International Standard for Neurological Classification of Spinal Cord Injury.
Exclusion criteria	• People undergoing treatment for cancers involving the spinal cord. • People undergoing treatment for clinically diagnosed mental health condition.
Sample size	N=20 adults with spinal cord injury
Participant characteristics	Age in years [Mean (SD)]: 49.95 (13.42) Sex (M/F): n=15/n=5 Time since diagnosis or injury in years [Mean (SD)]: Not reported, range 5-49

	Chronical neurological disorder category: Acquired spinal cord injury
Results	Themes as described in paper: • Lack of sexual support provision ○ All participants reported a paucity of sexual rehabilitation services in both inpatient and outpatient settings. This lack of education and information lead to decreased feelings of sexual preparedness, sexual competence and cognitive understanding. Furthermore, although healthcare professionals were noted as being key figures in the delivery of this education and support, people with spinal cord injury did not feel confident in approaching them, in their knowledge of the subject, in the accessibility of support, and in the aftercare available after discharge. When discharged from a service, people reported a complete lack of knowledge about sexual function, and this caused them to feel uncertain and confused. This feeling was compounded with difficulties with receiving additional support after discharge. Participants reported an avoidance in starting discussions relating to sex with healthcare professionals and felt that professionals also felt this awkwardness in bringing up the topic. ○ *“You try to search for anything for women after a spinal cord injury and there isn’t anything. I mean I have been told numerous times, “you have lost your function and that’s it, now you just have to accept that”. It was never discussed with me in the spinal unit." (page 54)* • Intervention recommendations ○ Although respondents reported different levels of readiness to explore sex, all agreed that more sexual rehabilitation education should be offered to inpatients. Further information should be available to people once they have been discharged. A group delivery for sexual rehabilitation interventions was felt to be inappropriate due to the diverse set of individual needs and requirements. Education and information support for sexual rehabilitation should be provided to both inpatients and outpatients. Participants reflected that targeted reading information on the subject should be made a priority to allow people to maintain their anonymity while seeking answers and advice. ○ *"The good thing about a book, like sexual function made easy for spinal cord injury, that’s more likely to get attention that anything else. It is private too and then people could seek advice if they wanted to." (page 54)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment and data collection methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Bennett, 2023

Bibliographic Reference	Bennett, E; Fletcher, A; Talbot, E; Robinson, L; Returning to education after childhood acquired brain injury: Learning from lived parental experience.; NeuroRehabilitation; 2023; vol. 52 (no. 4); 625-640

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** A multi-disciplinary rehabilitation service specialising in paediatric acquired brain injury **Aim** To explore the experiences of parents and carers of children with acquired brain injury during return to education, to identify barriers and facilitators to the process from their perspective and highlight key points for educational professionals to implement in their practices.
Data collection and analysis	**Data collection**

	Method: Quantitative survey with free-text responses completed by participants. Location: Not applicable. Format: Online (hosted on Survey Monkey). Forty-two item questionnaire with questions were devised by a Paediatric Neuropsychology Service, a Brain Injury Specialist, and a Neuro-oncology Outreach Nurse Specialist. **Analysis** Thematic analysis. All 4 researchers became familiarised with the data, with 2 of them subsequently generating initial codes and organising them into groups. All researchers checked the codes with original data, adding new ones and re-organising when needed. Final codes were agreed by consensus before collating them into themes and sub-themes through discussion and mapping. Themes were further refined and agreed upon by all researchers, before being finalised and named.
Recruitment strategy	Parents of children and young people meeting inclusion criteria were contacted by email or text message, and provided with a link to the survey. No further details reported.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Parents of children or young people attending specialist acquired brain injury neurorehabilitation service. • Attending between October 2017 and March 2020.
Exclusion criteria	Not reported
Sample size	N=31 parents and carers of children and young people with acquired brain injury
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported, age range 5-18 Sex of children and young people with chronic neurological disorders (M/F): n=19/n=12 Chronic neurological disorder category: Acquired brain injury

Results	Themes as described in paper: • Taking on the role of expert and advocate ○ Parents said that they needed to take on an advocate role with education providers, ensuring that schools understood their child's new requirements and when they could resume participation in certain activities. They also reported the need to challenge schools if support was not adequately provided. Parents reported that the process of getting an education care plan in place, and actioning it, took too long. Parents also often had to become an expert in the consequences and needs of paediatric acquired brain injury, without having the proper information on what support options could be provided in school. ○ *“Having to ask for support to be put in place but not knowing what can be offered and not being given a choice of different options” (page 630)* • Specialist support and information ○ Parents said that collaboration between healthcare professionals (for example, those working in acute care or neurorehabilitation specialists) and education professionals was important for education staff to understand their role within a child's rehabilitation, take note of recommendations from healthcare professionals, and know what further support was available if needed. ○ *No first-order quotes to support this theme.* • Role of specialists ○ Parents noted that information exchange and implementation of recommendations should be maintained throughout rehabilitation, and not simply in the initial stages. Parents noted that healthcare professionals were also very helpful when advocating for education support in schools. However, some parents reported instances where specialist advice was not followed and recommendations were not being implemented at all. ○ *“take note and implement recommendations from the Brain Injury Specialist and parents and maintain these over the long term of recovery not forge[t] them after the first few weeks” (page 631)* • The need for and availability of additional support in school ○ Parents of children with acquired brain injury reported that a lack of collaboration between healthcare professionals and education providers led to increased difficulty in accessing support for education. Support needs that had previously been agreed in joint meetings between rehabilitation professionals and education settings were not implemented when children returned to education. This lack of collaboration could happen

	between education settings as well (for example, when children are transferring from primary to secondary schools and their education care plan did not follow). Parents reported having to ensure that the correct information is handed over during this time. ○ Parents identified that the culture of the school affected how their child accessed educational support. Good practices included meetings with head teachers, knowing educational professionals were informed about acquired brain injury, and quickly implementing their education care plan. ○ *“. . . School staff gave promises and agreed to give support to my daughter on return to school when in meetings with myself and Brill team, but never followed through with agreed support when my daughter actually returned to school . . . the whole experience was disheartening.” (page 632)* • Hospital to school transition ○ Parents reported a lack of communication between hospitals and education settings. This meant that schools were unaware of a change in a child's needs, and poor knowledge of what support needs should be in place for them. Parents encouraged education professionals to communicate with rehabilitation professionals, to better understand what help and support is available through the NHS. ○ *“. . . there should have been some direct communication between hospital and school. School knew nothing about what had happened or what should be in place and simply relied on asking us what they needed to do.” (page 633)* • Communication with and within school ○ Parents felt that communication between themselves and education providers should remain open to ensure their child's current support needs are met, and continue to be met with any future needs. Parents reported also needing to be involved in communication within education systems, making sure information on needs and challenges are handed over when transitioning between settings. ○ *“Communication and cooperation with school is key. Be brave and don’t let your anxiety transfer to your child. Work with the ABI support teams to deliver advice to school. Be informed and draw on the information about ABI [acquired brain injury]. . . Look after yourself!” (page 633)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment and data collection methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Conneeley 2013

Bibliographic Reference	Conneeley Anne, Louise; Exploring vocation following brain injury: a qualitative enquiry; Social Care and Neurodisability; 2013; vol. 4 (no. 1); 6-16

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	UK
Setting and aim	**Setting** Neurological rehabilitation hospital and the community **Aim** To explore the vocational goals and ambitions of people with traumatic brain injury after discharge from a neurological inpatient setting.
Data collection and analysis	**Data collection**

	Method: Semi-structured interviews, written notes, observation and prolonged engagement. Interviews conducted at 3 time points: upon discharge from rehabilitation hospital to home; 6 months following discharge; 12 months following discharge. No information given on other forms of data collection. Location: • People with traumatic brain injury and family members: Varied but usually within the home. • Healthcare professionals working with people with traumatic brain injury: Rehabilitation hospital. Format: Individual, face-to-face, recorded and transcribed. Summaries of interview content and interpretation were given to participants for checking. **Analysis** Thematic analysis. Researchers familiarised themselves with the data by reading transcripts several times. Transcripts were compared within participant groups (person with traumatic brain injury, family member and rehabilitation professional) and between participant groups. Analysis was iterative and continued throughout the study, changing from a rehabilitation focus in the beginning to a sociological paradigm in later stages.
Recruitment strategy	Individuals meeting inclusion criteria were recruited as they were discharged home from an inpatient ward in the neurological rehabilitation hospital.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	• People with a diagnosis of traumatic brain injury and receiving inpatient neurological rehabilitation for at least 3 months. ○ Post-traumatic amnesia of greater than 24 hours. • Discharged back home under the care of a significant other. • Able to communicate verbally and understand verbal language enough to participate in the interview process. • Able to give informed consent.

Exclusion criteria	Not reported
Sample size	N=36 adults with traumatic brain injury plus family members Note: Study states '... members of the rehabilitation team were also recruited' (page 9) but no further details reported.
Participant characteristics	**Adults with traumatic brain injury, n=18** Age in years [Mean (SD)]: Not reported, age range 17-60 Sex (M/F): n=13/n=5 Time since injury: Not reported, but longest inpatient stay was 17 months Chronic neurological disorder category: Acquired brain injury **Family members of adults with traumatic brain injury, n=18** Age of people with chronic neurological disorders in years [Mean (SD)]: As above Sex of people with chronic neurological disorders (M/F): As above
Results	Themes as described in paper: • Rehabilitation and return to work ○ Respondents reported that return to work rehabilitation should tackle the challenges people will face when reintegrating into the work force. This will not only allow opportunities to learn about their current level of abilities and skills, but also develop and practice strategies to adapt their work practices through experimentation and feedback. ○ *“Lots of practice building up to his first work assessment. We put the pressure on for him to perform to his utmost and make it as realistic as possible. You know, he wore the clothes and he was quizzed doing it by his boss, he popped in, so I mean there has been so much support for him from his employer, to help him, which has been wonderful.” (page 11)* • Insight, awareness and personal autonomy

	○ Rehabilitation professionals reported that there is a need to adjust people's expectations and goals when returning to work (for example, if people are unaware of their own challenges or do not understand how this could impact their employment). There is a balance to strike between protecting people from potential harm if they underestimate their challenges and providing them with opportunities and maintaining engagement. ○ *"It's his visual scanning, it's not to do with his vision it's to do with his head injury. He does have difficulties when he's out in a busy environment, being able to size up the situation, visual information. If he's got to match stock with some computer input he's going to have difficulties searching and keeping track of information. He could operate computers, but only simple ones" (page 11)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of rehabilitation professional participants in all areas, poor reporting of how the relationship between researcher and participants was taken into consideration, lack of discussion about study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

De Dios Perez, 2022

Bibliographic Reference	De Dios Perez, Blanca; Radford, Kate; das Nair, Roshan; Experiences of people with multiple sclerosis at work: Towards the understanding of the needs for a job retention vocational rehabilitation intervention.; Work (Reading, Mass.); 2022; vol. 72 (no. 1); 303-313

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported **Aim** To explore the experiences of people with multiple sclerosis with remaining in employment and accessing vocational rehabilitation, to identify barriers and facilitators for this support.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Location: Not reported. Format: Face-to-face or via telephone, audio recorded and transcribed verbatim. **Analysis** Thematic framework analysis. Transcripts were uploaded to NVivo 12 and a codebook was developed using the research objectives, and headings taken from both the International Classification of Functioning, Disability and Health and Behaviour Change Wheel.
Recruitment strategy	Convenience sampling. Local multiple sclerosis charities and personal networks contacted individuals meeting inclusion criteria.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People with a clinician-confirmed diagnosis of multiple sclerosis who were in employment.

	- Healthcare professionals with experience of working with people with multiple sclerosis. - Employers with experience of working directly with or supporting other employers working with people with multiple sclerosis.
Exclusion criteria	Not reported
Sample size	N=20 adults with multiple sclerosis plus healthcare professionals and employers
Participant characteristics	**Adults with multiple sclerosis, n=10** Age in years [Mean (SD)]: 47.5 (7.74) Sex (M/F): n=2/n=8 Time since diagnosis in years: Not reported Chronic neurological disorder category: Progressive neurological disease **Healthcare professionals working with people with multiple sclerosis, n=6** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=4 occupational therapists, n=2 neurologists **Employers of people with multiple sclerosis, n=4** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=2 human resources employer relations advisors, n=1 human resources project manager, n=1 programme manager
Results	Themes as described in paper: - Working with MS: Support provided at work

  - People with multiple sclerosis noted that flexibility was important when providing adjustments in the workplace (for example, reducing work hours, changing physical aspects of a role, or providing opportunities to work from home. A better relationship with line managers often resulted in people being more satisfied with adjustments and believing employers were more accommodating.
  - *No first-order quotes to support this theme.*
- VR for people with MS: Intervention components
  - Respondents reported that employer engagement was an important part of vocational rehabilitation, discussing the impact of multiple sclerosis and what support they can offer their employees. It increases an employer’s desire to receive and implement information on reasonable adjustments. People with multiple sclerosis also expressed a wish for support when disclosing their condition to their employers.
  - *No first-order quotes to support this theme.*
- VR for people with MS: Attributes
  - Participants reported that raising awareness of available vocational support and implementation of these services should occur soon after diagnosis. This will allow the timely identification of environmental or disease-specific factors that might impact employment retention. This support should be reviewed as a person’s rehabilitation needs change.
  - *No first-order quotes to support this theme.*
- Barriers and facilitators: External factors
  - Participants reported that flexible support was key in delivering effective vocational rehabilitation. This could be as simple as signposting to additional resources if support is not readily available and ensures minimal disruption of the intervention on the lives of people with multiple sclerosis. A safety net should also be available to identify unmet rehabilitation needs and provide early referral to relevant services to address these needs.
  - *No first-order quotes to support this theme.*
- Barriers and facilitators: Individual’s characteristics

	○ Respondents felt it was important that the healthcare professionals are able to balance the expectations of both employees and employers, ensuring they understand the impact of the intervention on both parties and the likely outcomes. ○ *No first-order quotes to support this theme.*

MS: multiple sclerosis; N/n: number of participants; SD: standard deviation; VR: vocational rehabilitation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Poor description of recruitment methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

De Dios Perez, 2023

Bibliographic Reference	De Dios Perez, Blanca; das Nair, Roshan; Radford, Kathryn; A mixed-methods feasibility case series of a job retention vocational rehabilitation intervention for people with multiple sclerosis.; Disability and rehabilitation; 2023; 1-12

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK

Setting and aim	**Setting** In the community (study was part of a wider investigation into a vocational rehabilitation intervention designed to support employment in people with multiple sclerosis, delivered to people with the condition and their employers [including line managers, human resources, or occupational health]) **Aim** To explore the feasibility and acceptability of a vocational rehabilitation intervention specifically designed for people with multiple sclerosis.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Location: Online. Format: Audio recorded and transcribed verbatim. **Analysis** Thematic framework analysis. Transcripts were uploaded to NVivo 12. Coding was guided by main domains for the theoretical frameworks and final themes were discussed and agreed between the researchers.
Recruitment strategy	Convenience sampling. People attending a multiple sclerosis clinic at the NHS Trust hospital and multiple sclerosis charities were invited, and social media users. Participants with multiple sclerosis were informed that employers or line managers could also be involved in the intervention and were provided with a Participant Information Sheet to share with their employer if interested. Alternatively, a study researcher could contact employers with this information if individuals with multiple sclerosis agreed. Participants with multiple sclerosis were also asked if they wished to designate a healthcare professional involved in their usual care to provide more information on their condition as well as support throughout the trial.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• Individuals aged 18-65 years old with a diagnosis of multiple sclerosis and currently employed.

	○ Able to communicate in English and give informed consent. • Healthcare professionals of participants with multiple sclerosis, who were over the age of 18 years and gave informed consent. • Employers of participants with multiple sclerosis, who were over the age of 18 years and gave informed consent.
Exclusion criteria	• Individuals with multiple sclerosis who were planning on retiring in the next 6 months.
Sample size	N=22 adults with multiple sclerosis plus healthcare professionals and employers
Participant characteristics	**Adults with multiple sclerosis, n=15** Age in years [Mean (SD)]: 46.13 (9.58) Sex (M/F): n=3/n=12 Time since diagnosis in years [Mean (SD)]: Not reported, range 0.5-16 Chronic neurological disorder category: Progressive neurological disease **Healthcare professionals working with people with multiple sclerosis, n=4** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=3 neurologists, n=1 multiple sclerosis nurse **Employers of people with multiple sclerosis, n=3** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=3 line managers
Results	Themes as described in paper:

- Context
    - Healthcare professionals reported that, although they realised it was important to offer vocational rehabilitation for people with multiple sclerosis, they did not have the knowledge and expertise to provide this.
    - *“As doctors, I think it would be very tricky for us to also have that expertise, and be confident enough to deliver those interventions, when it is outside our area of expertise.” (page 7)*
- Employer engagement
    - A common issue reported at work revolved around managing relationships with employers, meaning people with multiple sclerosis were conflicted about including employers in their vocational rehabilitation. If they were involved, people thought the information shared with employers should be limited to prevent further discrimination.
    - *“I was a bit concerned in the early stages about including my employer. Because I feel like I have a supportive employer anyway, I kind of felt that it might be a little bit of a slur on them, that I wanted them included on it.” (page 8)*
- Intervention components and attributes: Support received
    - Participants stressed the importance of having a detailed assessment of rehabilitation needs in the workplace, to discuss specific barriers and available techniques to manage them.
    - *“I think it was the practical tips really, and talking through them with somebody, it is nice when somebody understands what is going on or says that these things happen, and they are real. It is Ok to feel like that.” (page 8)*
- Intervention components and attributes: Intervention tailoring
    - Participants believed that a longer rehabilitation intervention was needed to incorporate lengthier processes such as applications to government assistance schemes (for example, Access to Work).
    - *“With some things like “Access to Work,” the sort of length of time for the study might need to be more flexible so that you start and if things like that have to go back to Government or HR, you can have a sort of a number of hours in one month, and then come back to it.” (page 9)*
- Intervention components and attributes: Therapist’s attributes

	○ Participants reflected that rehabilitation interventions were more effective when professionals delivering them are knowledgeable about multiple sclerosis and employment law and are willing to collaborate with other services as needed (for example, human resources or legal representatives). ○ *"The person that is leading it [the intervention], is quite important as well. Because you [assistant psychologist] have done a lot of research, you have really good natural knowledge on the topics that I wanted advice about, but then also, you supplemented your natural knowledge with seeking advice from other professionals that would be more knowledgeable in a particular knowledge as well." (page 9)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Lack of consideration given to relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Dunford, 2020

Bibliographic Reference	Dunford, Carolyn; Cobbold, Clair; Ray, Ian; Wales, Lorna; The Information Gap for Children and Young People with Acquired Brain Injury.; Developmental neurorehabilitation; 2020; vol. 23 (no. 1); 1-8

Study Characteristics

Study type	General qualitative inquiry

Country/ies where study was carried out	UK
Setting and aim	**Setting** Residential and community-based brain injury rehabilitation services **Aim** To explore the information needs (including content and format) of children and young people with acquired brain injury throughout their childhood.
Data collection and analysis	**Data collection** Method: Email correspondence (n=1 participant), semi-structured interviews (n=3 participants), and focus groups (n=5 participants). Location: • Email correspondence: Online. • Focus groups: Not reported beyond ‘accessible central London location’. • Semi-structured interviews: Young person's home (n=2 interviews) and residential rehabilitation facility (n=1 interview). Format: • Email correspondence: No information reported. • Focus groups: Face-to-face and audio-recorded. Focus group questions were constructed around the results of the online questionnaire. • Semi-structured interviews: Face-to-face and audio-recorded. Topic guides were constructed from the focus group conversations with participants being provided a summary of the chosen topics. If new topics were introduced, open ended questions were posed by the researcher to develop these further. **Analysis**

	Recordings were transcribed verbatim. One researcher familiarised themselves with the focus group data, creating a coding structure that reflected the transcript themes and those previously identified in the survey. Codes were applied to the focus group transcript by 3 researchers using NVivo 10 software, checking reliability along the way, before also being applied to interview transcripts. Disagreements were resolved through discussion and consensus. Note: Study also recruited children and young people for postal and online questionnaires. This data did not undergo qualitative analysis and therefore these methods have not been included in the collection and analysis description.
Recruitment strategy	Initial questionnaire was posted to all children meeting the inclusion criteria, identified from discharge records by researchers and the Brain Injury Community Team. Adverts for participants were also disseminated through Brain Injury Rehabilitation's online information resource and social media platforms. After completion of the questionnaire, participants were asked if they would like to attend further focus groups. After completion of the focus groups, participants were asked if they would like to participate in further semi-structured interviews.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	Children and young people who had received residential or community-based rehabilitation from a UK brain injury rehabilitation facility: • Aged 6-18 years old. • Attended between 2009-2014.
Exclusion criteria	Not reported
Sample size	N=6 children and young people with acquired brain injury Note: Study recruited 16 children and young people but 10 of these only completed stage 1 of the study (online questionnaire). These data did not undergo qualitative analysis and therefore these participants have not been included in the review sample.
Participant characteristics	Age in years [Mean (SD)]*: Not reported, age range 9-17 Sex (M/F)*: n=1/n=4

	Time since diagnosis or injury in months [Mean (SD)]*: Not reported, range 4-13 Chronic neurological disorder category: Acquired brain injury *Characteristics only reported for n=5 participants
Results	Themes as described in paper: • Schools ○ Respondents reported a need for increased information on education options, including special schools, possible alternative routes into university, and special adjustments that could be offered in exam situations. Children with acquired brain injury also reported that information may need to be repeated throughout their education. They reflected that sometimes having a healthcare professional attend the school to talk about their education support needs was needed before these support needs were met. ○ *"Having information about special schools and things would just make you feel more comfortable about school." (page 6)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment, moderate value of research for current question.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Dyer, 2014

Bibliographic Reference	Dyer, Kerry; das Nair, Roshan; Talking about sex after traumatic brain injury: perceptions and experiences of multidisciplinary rehabilitation professionals.; Disability and rehabilitation; 2014; vol. 36 (no. 17); 1431-8

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Rehabilitation services **Aim** To explore healthcare professionals' views and experiences of sexuality-related discussions with people with traumatic brain injury.
Data collection and analysis	**Data collection** Method: Focus groups. Four x groups of 4-8 participants each, stratified by the team in which people worked. Sessions lasted on average 40 minutes. Location: Working base, during working hours. Format: Face-to-face, audio recorded and transcribed verbatim. Topic guides were developed using identified gaps in literature. Field notes were kept alongside recording to inform non-verbal communication and group interactions. **Analysis** Thematic analysis. Researchers familiarised themselves with the transcripts, identifying initial codes and categories along the way. These codes were then organised into themes before developing a thematic map to show the main themes and sub-themes.

Recruitment strategy	Purposive sampling. Participants were recruited from local traumatic brain injury or neurorehabilitation NHS teams and a national charity supporting people affected by brain injury. Managers and senior members of staff were contacted with information on the study, which was then distributed to professionals within the team.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	• Rehabilitation professionals working with people with traumatic brain injury.
Exclusion criteria	Not reported
Sample size	N=24 healthcare professionals working with people with traumatic brain injury
Participant characteristics	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=6 occupational therapists, n=5 support workers, n=3 psychological therapists, n=2 physiotherapists, n=2 case managers, n=1 doctor, n=5 'other' therapists
Results	Themes as described in paper: • Sexuality after TBI is a specialist issue ○ Healthcare professionals reported a lack of knowledge, skills and expertise that prevented them from starting conversations about sexuality and how they navigated them once raised (for example, deflection of the topic). Participants reported being referred to other specialists (either within a service or outside of one) for advice and support for sexual rehabilitation. They noted that further education and training would leave them feeling better prepared to deal with sexual issues. However, exactly what topics this training should cover were not detailed. One organisation did offer training on sexual reproduction, but respondents felt it was inadequate to cover the range of issues that might be raised. Similarly, lectures on the subject were thought to be insufficient to address the embarrassment factor surrounding conversations about sexual function. Instead, people recommended an exposure-based approach to strengthen conversation skills.

	○ *"P7: It's not really a proper course though [it's just like a-P1:2 [No. It's like a teaser sort of thing isn't it? P7:2 One day workshop that gives you very very basic information, and I think that sort of thing needs more formal training P2:2 Yeah P7:2 It's just sort of an awareness raiser" (page 3)* • Sexuality is a sensitive subject ○ Participants reported that sexuality is a sensitive topic that needs to be handled carefully. Some people felt that raising the issue may be seen as insensitive or inappropriate by some people with traumatic brain injury, which could affect their subsequent engagement in future rehabilitation. ○ *"P4:3 . . .particularly in the early days you don't want to upset them or intimidate them or make them feel uncomfortable, 'cos we get enough failed to attends P1:3 Mmm ((indicating agreement with P4:1)) P4:3 and people that don't comply to the treatment" (page 4)* • Practicalities of discussing sexuality ○ Participants reported that including questions on standard questionnaires or having prepared written information pamphlets would assist them in discussing sexual rehabilitation options with people. ○ *"I don't think they have had this identified. . . even on the information leaflet, whether we need to give that information leaflet about the unit, like our unit and say - look, these are the aspects, but if you want to discuss it, feel free to discuss it. So at least they are empowered to say, this is something they can discuss. . . Because actually the patient, they are not aware they are allowed to discuss that with us" (page 4)* • Roles and responsibilities ○ Participants did not wish to allocate a specific individual to address sexual rehabilitation concerns. Instead, they believed it was a person's choice as to who they wanted to discuss these matters with. However, 1 respondent reflected that this raised the risk of people assuming that someone else will take care of any concerns, which could lead to no one doing so. ○ *"P6: You kind of think it's a job for somebody else-like it's not necessary a physio ((physiotherapy)) problem, it's not necessarily an OT ((occupational therapy)) problem, but put us altogether and it is our problem. But I think you sort of expect somebody else to do it rather than (.) you yourself do it." (page 4)* • Organisational and structural issues ○ Participants reported that asking about sexual rehabilitation risked opening a 'can of worms', especially where there is a lack of knowledge or a lack of awareness of available specialist services to which people

	could be referred. Time and resource pressures within services mean that sexuality issues can be minimised in rehabilitation services. Unlike other rehabilitation issues, sexuality is not included in any formal outcome measurements or assessments which reflects this low prioritisation. ○ *"P1:1 I mean you might be asking a question with this, you know in this area, and erm and then you think what the hell do I do with it (laughs) ((laughter from others)). . .I mean I'm certainly aware that (.) our model is to deal with it ourselves or to refer on. And where do you refer on to?.. . I don't view it ((sexuality)) as being particularly more difficult to address than any of the others, but it's just that issue about not really being sure about where you take it P2:1 I'd agree. Yeah, not thought of it like that before" (page 5)*

N/n: number of participants; P: participant; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment and analysis methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Freeman, 2020

Bibliographic Reference	Freeman, Jennifer; Gorst, Terry; Gunn, Hilary; Robens, Sarah; "A non-person to the rest of the world": experiences of social isolation amongst severely impaired people with multiple sclerosis.; Disability and rehabilitation; 2020; vol. 42 (no. 16); 2295-2303

Study Characteristics

Study type	Phenomenological

Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community **Aim** To explore the experiences and views of social isolation in people with multiple sclerosis.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted on average 60 minutes. Location: At home. Format: Face-to-face, audio recorded and transcribed verbatim. Two pilot interviews were conducted initially to check the topic guides and procedure. No changes were made and data collection moved on to the remaining 14. All transcripts were included in the analysis. **Analysis** Thematic analysis. Transcripts were uploaded into NVivo 8 software and inductive coding performed to identify initial themes, which were then assessed across participants' accounts. Coding reliability checks were conducted by 2 authors, with the transcripts and initial themes discussed by 3 authors. Themes were collated and finalised. Participants were asked to comment on a summary of the key findings, and 2 participants were asked to confirm the contents of the final report.
Recruitment strategy	Maximum variation sampling (with regards to gender, age and level of disability). Potential participants were recruited using people with multiple sclerosis attending local support groups, who then passed on information regarding the study to other attendees who were severely impaired by their disorder and were socially isolated, or sent an invitation from their neurology consultant. An advert was also included in South West Impact of Multiple Sclerosis longitudinal cohort study newsletter.
Study dates	Not reported
Sources of funding	Not reported

Inclusion criteria	• People with a clinical diagnosis of multiple sclerosis, have an Expanded Disability Status Scale above 6.5 (restricted to walking short distances bilaterally assisted or using a wheelchair for mobility), and believed that their impairments impacted their access to external activities.
Exclusion criteria	• People who could not provide informed consent. • People with impairment difficulties that would affect their ability to participate in an interview.
Sample size	N=16 adults with multiple sclerosis
Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 38-72 Sex (M/F): n=7/n=9 Time since diagnosis in years [Mean (SD)]: Not reported, range 3-30 Chronical neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • ‘…I don’t even have a vision’: Potential eases of social isolation ○ The majority of respondents did not have a positive view of multiple-sclerosis group-based initiatives. Beyond their disorder, people reported not having anything in common with other members of the support group. Additional reasons were not wanting to hear the problems of other people with multiple sclerosis, not wanting to know what could be worse, and not wanting to hear positive messages if they were not feeling positive. Conversely, some participants felt as though the multiple sclerosis group helped them access other people who understand their disorder and therefore help them come to terms with their diagnosis. People reported logistical issues, which acted as a barrier to accessing centres (for example, transport availability and available carer support). Some participants reported that accessing direct payments could be beneficial in allowing people to do something 'normal' together such as going out for dinner. However, many found the system confusing and bureaucratic. Other participants reported that a consequence of their multiple sclerosis was a decreased ability to process the complexity of assistance systems. An additional barrier to accessing services was a perception that services were too busy and would not have resources to help decrease social isolation. ○ *“My brain’s not working as fast as it was, and I think I can’t handle all this, so I shut off.” (page 19)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Gibbs, 2022

Bibliographic Reference	Gibbs, Katie; Wilkie, Lowri; Jarman, Jack; Barker-Smith, Abigail; Kemp, Andrew H; Fisher, Zoe; Riding the wave into wellbeing: A qualitative evaluation of surf therapy for individuals living with acquired brain injury.; PloS one; 2022; vol. 17 (no. 4); e0266388

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Community neurorehabilitation service (comprised of Brain Injury Service, Vocational Stroke Service and General Neuropsychology Service) within a general hospital setting (study was part of a wider evaluation of the effects of a 5-week surfing intervention)

	Aim To explore the experiences of people with acquired brain injury when participating in a surfing intervention, and to suggest possible mechanisms for a resulting improvement in well-being.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted from 10 minutes 41 seconds to 45 minutes and 30 seconds, with an average 27 minutes 45 seconds. Location: Hospital (n=12) and not reported (n=3). Format: Face-to-face (n=12) and telephone (n=3), audio recorded and transcribed verbatim. In-person interviewees were allowed to bring a member of their support circle (for example, a parent or support worker). **Analysis** Thematic analysis. Transcripts were uploaded to ATLAS.TI, before initial coding was performed by 1 researcher according to a critical realist epistemological perspective. The researcher familiarised themselves with the transcripts to identify themes and sub-themes within and across a dataset. Themes were continually refined alongside a running narrative to contextualise the findings. Meaningful quotes were selected at this stage. Two other researchers contributed their interpretations to further develop themes.
Recruitment strategy	Purposive sampling. Participants were recruited from people attending 1 of the 3 neurorehabilitation services (Brain Injury Service, Vocational Stroke Service or General Neuropsychology Service), as part of their ongoing rehabilitation.
Study dates	July-October of 2018-2020
Sources of funding	Not industry funded
Inclusion criteria	• People aged 18 years or older with a clinical diagnosis of acquired brain injury, living in the community within the boundaries of the governing health board, able to engage in neurorehabilitation (according to treating healthcare professionals), and able to give informed consent.
Exclusion criteria	• People medically unfit to participate in physical activity.

Sample size	N=15 adults with acquired brain injury
Participant characteristics	Age in years [Mean (SD)]: 42.4 (12.88) Sex (M/F): n=10/n=5 Time since diagnosis or injury in years [Mean (SD)]: 2.75 (3.07) Chronical neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Building community through social connection ○ Participants reported that a group delivery facilitated a sense of belonging and mutual understanding of experiences. Other group members could also provide emotional support. This increased feeling of relatedness helped to facilitate a sense of community, social cohesion and teamwork, whilst decreasing a sense of social isolation. ○ *"What was good about it was you could see other people—not that I am trying to put them down—but they were falling off as well as I was falling off. Yet, when each individual person did it, it was a group where we all applauded then, which was like bonding. You weren't trying to put somebody down—we were hoping that they could get up!" (page 12)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Lack of discussion about study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Hooson, 2013

Bibliographic Reference	Hooson, J Marian; Coetzer, R; Stew, G; Moore, A; Patients' experience of return to work rehabilitation following traumatic brain injury: a phenomenological study.; Neuropsychological rehabilitation; 2013; vol. 23 (no. 1); 19-44

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported **Aim** To explore which factors help to support return to work for people experiencing multiple impairments and disabilities after traumatic brain injury.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. No further details reported. Location: Not specified. Format: Not specified. **Analysis** Interpretative phenomenological analysis. Researchers familiarised themselves with the transcripts through reading and re-reading, before developing main themes and sub-themes.

Recruitment strategy	People with traumatic brain injury and meeting the inclusion criteria were identified from people with traumatic brain injury registered with the North Wales Brain Injury Service. No further details reported.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	• People with traumatic brain injury and aged 18-65 years. • People who had been in paid employment prior to their injury, participated in specialist vocational rehabilitation and attempted to return to work after their injury (regardless of success). • Completed Awareness Questionnaire before enrolment, with results comparable to those of key clinician and significant other.
Exclusion criteria	Not reported
Sample size	N=10 adults with traumatic brain injury
Participant characteristics	Age in years [Mean (SD)]: 43.1 (13.75) Sex (M/F): n=8/n=2 Time since injury in months [Mean (SD)]: 65.7 (27.85) Chronic neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Factors impacting on the rehabilitation period: Therapeutic relationship ○ Participants appreciated learning about available alternatives when they could not return to their previous role or employment. ○ *"[RTW rehabilitation] has shown me there is . . . other avenues . . . as that part of my life last year I just thought that is it . . . It's over. Done with. Never be repeated. But you've [clinicians involved in RTW*

rehabilitation] shown me that with small steps . . . baby steps, I can keep moving forward and other doors will open for me . . . so there is light at the end of the tunnel." (page 32)

- Participants' perceptions of assistive elements of RTW rehabilitation: Vocational
    - Participants reported that workplace assessments were very helpful, when followed up with the occupational health department. Holistic vocational rehabilitation (including occupational health, employment managers, occupational therapists and psychologists) can not only ensure people return to work successfully but can also prevent deterioration in other life areas. This support should continue for as long as needed.
    - *". . . My employers also told me that they valued the input that you [occupational therapy and psychology] were able to give them because effectively it was unchartered territory for them (. . .) and they probably would have assumed I had been signed off by a doctor as being fit for work and there was no real reason to do anything other than the standard policy for someone who has been on long-term sick (. . .) So it's pretty clear that if I hadn't had the input of the brain injury unit I would certainly run the chance of getting back into very . . . very . . . serious health problems very quickly." (page 33)*
- Participants' perceptions of assistive elements of RTW rehabilitation: The personal perspective
    - Participants said that accessing comprehensive return to work services early on in their rehabilitation could also help them adjust to their diagnosis in other areas of their lives.
    - *"[If I had attended the RTW rehabilitation earlier than I did] . . . Mmm . . . Well I think it would have helped me over the initial shock (. . .) Of realising that the life I had was finished and that there was a new life to go on with . . . ummm of what, how and when." (page 33)*
- Participants' perceptions of assistive elements of RTW rehabilitation: Faith in clinicians' knowledge and guidance
    - Vocational rehabilitation should include realistic goals with objective and measurable outcomes. If people find it difficult to set their achievable goals, healthcare professionals should assist them. A multidisciplinary team approach was also valued in order to ensure that potential vocational rehabilitation needs can be identified by other professionals, and appropriate referrals made. This support should continue even after the initial intervention has finished.
    - Participants appreciated a group setting for return-to-work rehabilitation, allowing them to share experiences and increase engagement in the rehabilitation process. Another benefit was increased socialisation.
    - *". . . Looking back with hindsight, if I'd have taken my own course, I hate to think where I would be now. Because I certainly would have gone back to work on a full-time basis, and would certainly have gone back*

	to work to my old job description (. . .) So it's pretty clear that if I hadn't had goals set by the brain injury unit I would certainly have run the chance of getting back into very . . . very . . . serious health problems very quickly" (page 34) • Participants' perceptions of assistive elements of RTW rehabilitation: Familial involvement ○ Respondents acknowledged the importance of unpaid carers in supporting people to attend their return-to-work rehabilitation (for example, by providing transportation or confirming appointments). ○ *"Everything I needed. I'd either, if I could do it myself; they'd not do it for me, but assist me in doing it . . . little things like confirming appointments with you . . . I'd forget. My mother would remind me and make sure I'd get on the phone and sort it out with you. And bank issues, eye tests, other doctors' appointments, hospital appointments. She'd take me there because I couldn't get the bus myself. So . . . they ferried me around. I mean, it's all well you offering me appointments in Colwyn Bay. But getting there. I couldn't have done that by myself. So I know there is hospital taxis and transport, but I don't know how reliable they are so . . . yeah, they got me there, took me around, fed me, gave me quite a bit of stability." (page 37)*

N/n: number of participants; RTW: return to work; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment, data collection, and analysis methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Hoskin, 2021

Bibliographic Reference	Hoskin, Janet; Troubling norms? Adults and teenagers with a life-limiting impairment in Denmark and England talk about their lives, support and future plans.; European Journal of Special Needs Education; 2021; vol. 36 (no. 3); 329-343

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Hospices in England - within Action Duchenne's 'Takin' Charge Transition to Adulthood' project **Aim** To explore and compare the experiences of young men with Duchenne muscular dystrophy in Denmark with those in England, when transitioning to adulthood. Note: The experiences of participants in Denmark are outside of protocol population and have not been extracted or analysed.
Data collection and analysis	**Data collection** Method: Focus groups (n=3 groups) semi-structured interviews (n=2). Location: Not specified. • Focus groups: Hospices and the international conference of the charity delivering Takin' Charge. • Semi-structured interviews: At home. Format: • Focus groups: Face-to-face, audio recorded and transcribed verbatim. • Semi-structured interviews: Online via Skype, audio recorded and transcribed verbatim. **Analysis**

	Thematic analysis. Researchers familiarised themselves with transcripts from both countries at once, identifying shared themes. Initial codes were developed and revised through subsequent conversations with a small steering group of young men with Duchenne muscular dystrophy.
Recruitment strategy	Participants self-referred to the study through the 'Takin' Charge Transition to Adulthood' project.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	• Young men with Duchenne muscular dystrophy aged 14-19 years who participated in the 'Takin' Charge Transition to Adulthood' project. • Members of the steering committee from the 'Takin' Charge Transition to Adulthood' project.
Exclusion criteria	Not reported
Sample size	N=24 young men with Duchenne muscular dystrophy
Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 14-47 Sex (M/F): n=24/n=0 Time since diagnosis: Not reported Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Having normative aspirations ○ Vocation services were reported to have a lack of ambition and low expectations of young men with Duchenne's. Participants reported not being offered advice on employment and being unaware of alternatives to traditional employment roles that may be more suitable to their needs (for example, self-employment).

	○ Participants reported that building friendships was a primary motivation for joining the Transition project. Although reluctant to expand on the topic, all respondents highlighted the importance of the sex and relationships workshops. ○ *“Absolutely nowhere else is doing this. Like you know if a person with DMD [Duchenne muscular dystrophy] went anywhere else they would just be told they shouldn’t work, just not bother basically, so I think that it’s been vital to look at this.” (page 335)* ○ *"No-one is having the conversation and saying that boys with my condition can get girlfriends" (page 335)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of recruitment, data collection, and analysis methods, lack of discussion regarding credibility (including the impact of recall bias on findings), lack of discussion about study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Jarvis, 2022

Bibliographic Reference	Jarvis, Laura; McConville, Kevin; Devereux, Sonia; O'Riordan, Jonathan; Let's talk about sex(ual) wellbeing! Staff perceptions of implementing a novel service for people with Multiple Sclerosis.; Multiple sclerosis journal - experimental, translational and clinical; 2022; vol. 8 (no. 1); 20552173211072285

Study Characteristics

Study type	Case study
Country/ies where study was carried out	UK
Setting and aim	**Setting** A novel multiple sclerosis pelvic health service in Scotland (part of rehabilitation services) **Aim** To explore healthcare professionals' experiences and views on implementing a regional multiple sclerosis pelvic health service, and provide lessons learned for future service provision.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Location: Not reported. Format: Face-to-face or telephone, audio recorded and transcribed. **Analysis** Thematic analysis. Using an inductive approach, 1 researcher familiarised themselves with the transcripts before performing initial coding, which was then discussed and resolved into themes and sub-themes with a 2nd researcher.
Recruitment strategy	Purposive sampling. Participants were recruited from regional multiple sclerosis team involved in the study by the departmental secretary.
Study dates	December 2020
Sources of funding	Not industry funded
Inclusion criteria	• Healthcare professionals working within the study multiple sclerosis team and involved in the delivery of annual multiple sclerosis reviews.

Exclusion criteria	Not reported
Sample size	N=5 healthcare professionals working with people with multiple sclerosis
Participant characteristics	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=3 specialist multiple sclerosis nurses, n=1 consultant neurologist, n=1 general practitioner with a special interest in multiple sclerosis Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Service tensions – unmet needs and time pressures ○ All participants reported that sexual health was neglected in their multiple sclerosis reviews, due to a lack of time, knowledge and availability of services and intervention options for onward referral. ○ *"…truthfully this is a very time-consuming activity rather than one to one discussion with patients which is more valuable…" (page 3)* • Service tensions – clinic purpose and future developments ○ Some participants suggested including questions on sexual wellbeing in annual review appointments, which can then be used to refer people on to relevant rehabilitation services. ○ *"So, I think it's probably important that we have a good way of making sure that we note down…in their annual review…and we refer them…" (page 3)* • Patient needs – healthy relationships and gender approaches ○ Some healthcare professionals reflected that they were reticent about discussing sexual wellbeing and rehabilitation with people of the opposite sex. ○ *"I think as a nurse we don't engage enough with in getting to the nitty gritty aspect of discussion particularly with a male" (page 4)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of data collection and analysis methods, lack of discussion regarding credibility, lack of discussion about study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Jellie, 2014

Bibliographic Reference	Jellie, Bronwyn; Sweetland, Joanna; Riazi, Afsane; Cano, Stefan J; Playford, E. Diane; Staying at work and living with MS: A qualitative study of the impact of a vocational rehabilitation intervention.; Disability and Rehabilitation: An International, Multidisciplinary Journal; 2014; vol. 36 (no. 19); 1594-1599

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK
Setting and aim	**Setting** Occupational therapy led vocational rehabilitation intervention (part of a wider study investigating the effectiveness of the intervention, which was designed for people with multiple sclerosis and their employers and included assessment and

	interventions to address barriers to work caused by multiple sclerosis, referral to other rehabilitation specialties if needed (including Access to Work scheme), and education on legal rights regarding their disabilities. **Aim** To explore people's experiences while completing a vocational rehabilitation intervention designed for people with multiple sclerosis, and identify which factors were the most helpful.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted 1 hour on average and were completed 2-8 weeks after intervention completion. Location: Home and hospital. Format: Via telephone call, recorded and transcribed verbatim. **Analysis** Constant comparative thematic analysis. Transcripts were uploaded into MAXQDA programme before undertaking line by line coding, with codes assigned based on words and phrases found in the text. One researcher (not involved in the intervention delivery) used constant comparative analysis to compare relationships within and between codes, before being organised into themes across interviews. Each data piece was coded into as many categories as needed. A selection of transcripts were then read and coded by 2 other researchers (also not involved in the intervention) to check for accuracy and consistency, before discussing and agreeing emerging themes. Final themes were achieved using full consensus.
Recruitment strategy	Participants recruited from those who took part in the initial study.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Not reported
Exclusion criteria	Not reported

Sample size	N=19 adults with multiple sclerosis
Participant characteristics	Age in years [Mean (SD)]: Not reported, median 40, age range 24-63 Sex (M/F): n=4/n=15 Time since diagnosis in years [Mean (SD)]: 6.3 (SD not reported) Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Understanding my symptoms and their management in the workplace ○ The majority of participants were unaware of the 'Access to work' taxi scheme run by the Department of Work and Pensions. While not every participant accepted the need to join the scheme, those that did found it helpful, particularly if they had reduced mobility and long journeys to their workplace. Participants also reported worries that multiple sclerosis would decrease their cognitive functioning (especially memory and concentration) or organisation and management of work tasks. An assessment with a neuropsychologist and subsequent implementation of adjustment strategies gave these people reassurance that these challenges could be suitably managed at work. ○ *“The main thing was the taxi to work which picks me up in the morning and drops me off at a particular building. I am getting to work fresh during the day obviously it is hard and I have to travel the tube bus and down stairs and in the evening I get the taxi home so that has made a tremendous impact” (page 1596)* • Removing my anxieties ○ Participants reported that the initial meeting with occupational therapists was helpful to share their concerns and anxieties about returning to work. These stressors (for example, work hours, health and safety issues, and finances) could then be addressed throughout the intervention, usually with a workplace visit to meet with employers. ○ *“I think it was helpful for me to point me back in the right direction because my fears since the moment of diagnosis was of sort of unravelling and I became submerged with worries about the whole thing and it was useful in that respect. . . . . It was constructive.” (page 1597)* • Understanding and influencing my employer

	○ Participants reported that employers were more likely to respond to requests for reasonable adjustments in the workplace if they came from a professional, as they were perceived to have more authority. Having a rehabilitation professional in the workplace also gave an opportunity to clarify expectations of employers and negotiate reasonable accommodation issues. Some respondents reported that this support in negotiations could be passive, as the presence of a healthcare professional increased people's confidence in discussing these challenges with their employers themselves. Where employers attempted to dismiss requests for reasonable adjustments, healthcare professionals can act as an advocate in these situations and give further information and signposting on legal and other support. ○ *“. . . the employer is inclined to speak to a more official person who knows more about MS [multiple sclerosis] than to speak to your employee. You don’t want to offend them, you don’t want to upset them . . . you want to be helpful but I found that the most useful. Talking to somebody about work and coming with me to work was the best thing” (page 1597)* • Managing my loss of confidence ○ Respondents reported that education on legal rights (especially around reasonable adjustments and disclosure) led to people feeling a greater sense of empowerment when advocating for themselves in the workplace. Information on what choices are available allows people to make informed decisions about managing their disability with maintaining employment. ○ *No first-order quotes to support this theme.* • Having professional support ○ Participants highlighted the importance of the support of rehabilitation professionals throughout the return-to-work intervention. They felt as though they made the process more official for employers. Education was also noted as an important aspect of the intervention, giving information on different options and talking through how these might impact future plans. ○ *“It is just like if somebody else speaks for you a little bit and I think also for my boss to have some sort of official person there. I think for them it was quite good. You know there is not just the patient there is some person from the clinic, just to have a more authoritative figure there.” (page 1597)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Jones, 2019

Bibliographic Reference	Jones, Una; Hamana, Katy; Vougioukalou, Sofia; Jones, Mel; Busse, Monica; Exploration of a Co-Production Approach to Developing a Walking Group with People with Huntington's Disease.; Med one; 2019; vol. 4 (no. 5); e190022

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community (part of a 5-month trial of a supported walking group for people with Huntington's disease) **Aim** To explore the experiences of people with Huntington's disease and service providers when co-producing a walking group for people with Huntington's disease.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Carried out after 8th walk.

	Location: At home (n=2) and at university (n=4). Format: Face-to-face, audio recorded and transcribed verbatim (along with field notes). Photos taken during the walk were used throughout the interview as prompts. **Analysis** Thematic analysis. An inductive approach was taken, starting with familiarisation of the transcripts followed by double coding by identifying segments of text, assigning codes, and collating them into themes, which were then discussed between the 2 researchers. Themes were then finalised and named.
Recruitment strategy	• For people with Huntington's disease: Convenience sampling. Participants were recruited by a local specialist Huntington's Disease Association advisor through regional Huntington's disease meeting groups and a poster advert. • Specialist Huntington's Disease Association advisors: Not reported but involved in the delivery of the walking group. • Project officers from Let's walk Cymru: Not reported but involved in the delivery of the walking group.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People with Huntington's disease: People who were able to walk independently for 20 minutes (either with or without a walking aid) and to get up from the floor unaided. • Specialist Huntington's Disease Association advisors: Not reported. • Project officers from Let's walk Cymru: Not reported.
Exclusion criteria	Not reported
Sample size	N=6 people with Huntington's disease plus social care professionals
Participant characteristics	**People with Huntington's disease, n=3** Age in years [Mean (SD)]: Not reported

	Sex (M/F): n=2/n=1 Time since diagnosis: Not reported Chronic neurological disorder category: Progressive neurological disease **Social care professionals working with people with Huntington's disease, n=3** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=2 project managers from Let's walk Cymru, n=1 Specialist Huntington's Disease Association advisor
Results	Themes as described in paper: • Barriers ○ Both people with Huntington's disease and healthcare professionals identified transport to the walking location as a barrier to participation. People with Huntington's disease were also mindful of themselves and loved ones seeing people in more advanced stages of the disease. Other barriers identified were travel costs, negative expectations of the walking group and fitness levels needed for participation. ○ *"… the thought of being with other people that are at different stages … is he worse than I am …." (page 6)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of data collection and analysis methods, lack of discussion regarding credibility, lack of discussion about study value.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Highly relevant

Kelly, 2023

Bibliographic Reference	Kelly, Gemma; Wales, Lorna; Owen, Louise; Perkins, Alison; Young People's Experiences of Returning to Physical Leisure Activities after a Severe Acquired Brain Injury.; Physical & occupational therapy in pediatrics; 2023; vol. 43 (no. 4); 389-402

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community **Aim** To explore the experiences and views of young people re-engaging in physical leisure activities after acquired brain injury.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted between 25-45 minutes. Location: At home (n=5) and rehabilitation centre (n=2). Format: Face-to-face, audio recorded and transcribed verbatim. Four participants chose to have a parent sitting in on their interview, the remaining interviews were conducted individually. A topic guide was developed with a young person with

	acquired brain injury and their parent before being discussed and amended during conversations with the rest of the research team, 3 other young people with acquired brain injury and their parents (not included in analysis). The final guide was piloted with another young person with acquired brain injury (not included in analysis). **Analysis** Thematic analysis. Using an inductive and reflexive approach, a researcher familiarised themselves with the transcripts before identifying initial codes and themes. Field notes were used alongside the transcripts to better inform analysis. Occupational therapists and psychologists were involved in a discussion of the themes to ensure different clinical backgrounds were used in the interpretation of data. Final themes are then further refined and named by 1 researcher, before being discussed with the entire team.
Recruitment strategy	Participants meeting inclusion criteria were mailed an invitation to participate. No further details reported.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• Young people aged 14-19 years old with severe acquired brain injury (acquired between ages 11-17), with rehabilitation needs and meeting the NHS England criteria for category A or B funding. ○ Discharged from study specialist neurorehabilitation unit 1-3 years before the study and able to participate in interviews on discharge from rehabilitation and provide informed consent (or parental proxy for participants younger than 16).
Exclusion criteria	Not reported
Sample size	N=7 young people with acquired brain injury
Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 14-19 Sex (M/F): n=5/n=2 Time since diagnosis or injury: Not reported Chronic neurological disorder category: Acquired brain injury

Results	Themes as described in paper:
	- I Can't Do It Alone
	  ○ Parents were needed to find and organise activities, as well as provide transportation (which could be a long distance for disability sport) and support for young people while participating in activities. Healthcare professionals could support young people by finding activities for them to participate in, assisting them with financial and accessibility support, and checking eligibility criteria. This support could range from advice to in-person support. Teachers and other support adults from their community also supported young people, encouraging them to try activities if they were reluctant. Conversely, other people could also act as barriers to accessing activities. Examples included provision of accessible tricycles only at certain times, and failure to complete risk assessments.
	  ○ *"I hadn't been able to do it because they hadn't done a risk assessment" (page 396)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Poor description of recruitment methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Learmonth, 2013

Bibliographic Reference	Learmonth, Y C; Marshall-McKenna, R; Paul, L; Mattison, P; Miller, L; A qualitative exploration of the impact of a 12-week group exercise class for those moderately affected with multiple sclerosis.; Disability and rehabilitation; 2013; vol. 35 (no. 1); 81-8

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK
Setting and aim	**Setting** Group exercise programme for people moderately affected by multiple sclerosis (within a wider study of the effectiveness of the intervention) **Aim** To explore the experiences of people moderately impaired by multiple sclerosis taking part in a group exercise intervention and the consequences of participating in exercise and group exercise, and identify internal and external barriers to participating in exercise.
Data collection and analysis	**Data collection** Method: Focus groups. Two groups held during week 12 of the exercise intervention (Site A, 5 participants; Site B, 9 participants). Location: Not reported. Format: Face-to-face, audio recorded, and transcribed verbatim. A topic guide was developed based on a review of multiple sclerosis literature, focus group literature, and exercise in multiple sclerosis literature. Analysis of focus group A findings led to the modification of the guide for focus group B. **Analysis** Thematic content analysis. Using a general inductive approach, data were sorted and categorised. One researcher carried out the initial analysis after familiarising themselves with the data. These were then coded to identify initial relevant topic areas, with consistency checking performed across transcripts. Topic areas were collated into main themes and sub-themes, with representative quotes chosen. Focus groups were analysed separately, similar themes were identified across the groups, and then merged. Two researchers then discussed, refined, and finalised the themes.

Recruitment strategy	Participants were recruited through a regional Managed Clinical Network for multiple sclerosis.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People with a clinical diagnosis of multiple sclerosis, an Expanded Disability Status Scale score between 5 (able to ambulate for approximately 200 metres without aid or rest) and 6.5 (able to ambulate for approximately 20 metres with constant bilateral assistance without rest), and a Mini Mental State Examination cognition score of 24 or over.
Exclusion criteria	• People experiencing an increasing severity in multiple sclerosis symptoms within the previous 3 months. • People with a medical condition that prevents participation in exercise intervention.
Sample size	N=14 adults with multiple sclerosis
Participant characteristics	Age in years [Mean (SD)] *: • Focus group A: 54.2 (SD not reported), age range 45-62 • Focus group B: 51.0 (SD not reported), age range 40-68 Sex (M/F): n=4/n=10 Time since diagnosis in years [Mean (SD)] *: • Focus group A: 14.8 (SD not reported), range 11-18 • Focus group B: 14.8 (SD not reported), range 4-33 Chronic neurological disorder category: Progressive neurological disease *Characteristics only reported by focus groups, not for whole sample
Results	Themes as described in paper:

- Social support
    - Participants reported that group settings allowed them to exercise in an encouraging environment that motivated them, improved their beliefs about their condition and enabled them to foster new friendships. Some people had never met others with their disorder, so the disease specific nature of the exercise class facilitated this.
    - *"Good to get out and about and meet people . . . We're all the same, there is nobody any different, which was a bonus, because sometimes it's quite, when you see super fit people, it's a wee bit. . . ; Depressing, maybe?" (page 84)*
- Venue
    - While some respondents did not report issues with accessing the local venue, others reported a lack of disabled parking spaces and problems with transport. This in turn affected their ability to participate in the class.
    - *"Well I would have had transport problems but [another participant] lives around the corner from me and . . . he brings me down." (page 84)*
- Class structure
    - Participants praised the range of exercises included in the class, which provided aerobic, resistance and balance options at different levels of intensity.
    - *"I was really impressed with the fact that there were [exercise] options for different levels of difficulty and because you were writing things down [progress cards] at what level you had been exercising at. It was encouraging because after a few weeks you could look back and see, oh, yes I am getting better." (page 84)*
- Barriers to exercise: Psychosocial factors/social stigma
    - Participants reported that negative attitudes and poor knowledge about multiple sclerosis among healthcare and leisure professionals had led to them not accessing support for exercise in the past. Additionally, exercising alongside healthy people was a deterrent to participation as people felt a sense of otherness and that they had to explain their disorders and physical symptoms.
    - *"I felt that the individual trainers [in previous exercise experiences], although they were very sympathetic they didn't really have an understanding, they were frightened as well . . . they were sort of saying well you can't do this and you can't do that. I would be like, oh well, I won't go at all." (page 85)*

	- Barriers to exercise: Lack of service ○ Respondents reported that there was a lack of available opportunity to exercise and they wanted to continue their exercise classes after the study period. ○ *"I feel with MS [multiple sclerosis] you need it [exercise] all the time, you need it either once a week, or once a fortnight. You can't stop because.. you need to do this, you know all the time. [The NHS rehabilitation centre] couldn't obviously do that for us. This is a wee outlet for us all, and I think it would be good for us all if it continued." (page 85)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Lack of discussion about study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Mullin, 2018

Bibliographic Reference	Mullin, Rebecca L; Chaudhuri, K Ray; Andrews, Thomasin C; Martin, Anne; Gay, Stella; White, Claire M; A study investigating the experience of working for people with Parkinson's and the factors that influence workplace success.; Disability and rehabilitation; 2018; vol. 40 (no. 17); 2032-2039

Study Characteristics

Study type	Grounded theory

Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported **Aim** To explore the factors influencing workplace success (including relationships with employers and the provision of reasonable adjustments) in people with Parkinson's disease.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Location: Not reported. Format: Not reported if interviews held face-to-face, but were recorded and transcribed. Completed transcripts were checked with participants for accuracy and interpretations. **Analysis** Grounded theory. One researcher familiarised themselves with the transcripts before open coding line-by-line. Focused coding was subsequently performed, collating frequent and significant codes and merging them into main and sub-themes. Axial coding was then used to describe the relationships between main and sub-themes. Coding consistency was checked throughout analysis by checking interpretations with participants during interviews, and discussions between the research team during coding.
Recruitment strategy	Participants recruited via email advertising to members of a regional Parkinson's disease charity database or through referral from 4 Parkinson's specialist clinicians located at 2 urban teaching hospitals.
Study dates	Not reported
Sources of funding	Not industry funded

Inclusion criteria	• People with a clinician diagnosis of idiopathic Parkinson’s disease, and in current employment.
Exclusion criteria	• People with significant co-morbidity that affects their ability to work. • People with insufficient cognition or English language comprehension to participate in an interview.
Sample size	N=17 adults with Parkinson’s disease
Participant characteristics	Age in years [Mean (SD)]: Not reported, median 53.5, age range 39-77 Sex (M/F): n=9/n=8 Time since diagnosis: Not reported • Symptom duration in years [Median (range)]: 6 (1-11) Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • The role of internal factors: Coming to terms with the Parkinson’s diagnosis ○ Participants reported a bias of healthcare professionals talking about long-term options with their disability, assuming that people with Parkinson's will not be working in the near future. ○ *“Coming to terms with the Parkinson’s diagnosis I think, it didn’t help that when I got diagnosed (consultant) blurted out, ‘We think you’ve got Parkinson’s. Oh you look shocked… you won’t be working 5 years down the line, you will be confined to the wheelchair,’… that has pretty much stuck with me I think… I keep waiting for the time that I can’t work, I can’t do everything you know…mostly I’m (pause) not adjusted to it but (pause) I feel… okay is not the right word either. I’m living with it. I’m coping with it. I’m doing okay.” (page 2035)* • The role of internal factors: Being able to control Parkinson’s in the workplace ○ The pathway following a disclosure of Parkinson's differed between companies. In some, it might trigger formal assessments of need and potential adjustments while in others, this lay at the discretion of immediate line managers. Flexible work arrangements could be outright declined, or misinterpreted so that the level of flexibility was not enough to manage symptom variability. Structured pathways including multiple professionals (for example, managers, occupational health services, human resources, external disability or

union representatives) could often be found in larger companies. A prime example had clear internal referral pathways (including occupational health and human resources), accessibility roadshows to facilitate trials of assistive equipment, access to external disability services, and an internal disability network providing peer support from people with other long-term conditions. However, most people found that strategies suggested by their employers were either not appropriate for their needs or not implemented.

  - Some respondents reported that they did not appreciate having to use adaptive equipment in group environments, as it could draw attention to their disabilities. People liked the opportunity to design and implement their own adaptive strategies to ensure they were personalised to their own needs. Additionally, participants found it helpful to educate colleagues on their condition and needs.
  - *"Dragon (voice recognition software) will work in a noisy environment but to make it work, I would need to talk more loudly than I normally would do so I feel like a #### reading every punctuation mark to the machine." (page 2036)*
- The role of external factors: The influence of the line manager
  - Participants reported that line managers were gatekeepers in receiving reasonable adjustments in the workplace (for example, if they did not feel a request was appropriate), when occupational health or human resource departments were not involved in the requests. In these cases, decisions whether to provide certain adjustments were subjective and made based on how the provision would affect the role. If managers championed equality practices and had access to knowledge about Parkinson's disease, they were more likely to grant requests.
  - *"A month before I went off sick my manager said that we need to have a chat about hours and working. She said I want you to work 8.30–4.30 and I said I was going to find that a bit tough, you know with the Parkinson's… How about if I could do flexible, starting from 8, coming in by 9.30 depending on how I am feeling? And that is when she said, 'No. I want it done like this and if you are not well enough to come in, you go off sick'" (page 2036)*
- The role of external factors: The influence of law, workplace policies and available resources
  - All respondents reported that they knew about the legal protection within places of employment, but that these were not necessarily enforced. Similarly, people received conflicting information on how this protection affected their situation, and what they could expect. Company policy also affected the type and extent of workplace adjustment measures offered, with private companies and charities being more willing to engage in the rehabilitation process compared to the public sector.

	○ *No first-order quotes to support this theme.*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Salas, 2021

Bibliographic Reference	Salas, Christian; Casassus, Martin; Rowlands, Leanne; Pimm, Steve; Developing a model of long-term social rehabilitation after traumatic brain injury: the case of the head forward centre.; Disability and rehabilitation; 2021; vol. 43 (no. 23); 3405-3416

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Head Forward Centre - a day centre for people with traumatic brain injury, offering activities to encourage social rehabilitation

	Aim To explore the reasons of people with chronic traumatic brain injury for attending Headway and their experiences of activities offered by the centre, and to propose a theoretical long-term social rehabilitation programme model for traumatic brain injury.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted on average 30 minutes. Location: Head Forward Centre. Format: Face-to-face, recorded and transcribed verbatim. Interview schedule was developed using a review of the literature on acquired brain injury. **Analysis** Thematic analysis. Transcripts were exported into an Excel spreadsheet prior to coding, before being read and re-read by 2 researchers. Data were coded in their entirety, followed by discussion with both researchers and collating codes into a thematic table. Initial themes were then refined, names finalised, and example extracts were selected to accompany findings. A summary of findings was then presented to a focus group of Head Forward Centre attendees to agree with the themes.
Recruitment strategy	Purposive sampling. Participants recruited from the Head Forward Centre. No further details reported.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	Not reported
Exclusion criteria	Not reported
Sample size	N=12 adults with traumatic brain injury

Participant characteristics	Age in years [Mean (SD)]: 49 (9.2) Sex (M/F): n=10/n=2 Time since injury in years [Mean (SD)]: 17 (8.3) Chronical neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Safeness: HFC as an emotionally safe and predictable milieu ○ Participants frequently mentioned the emotional support developed with peers and volunteers at the centre throughout the years. Volunteers were not considered to be outsiders; rather they understood what living with a head injury was like and could advise on difficulties experienced by service users. They also helped to keep the environment of the centre familiar and predictable, which was a safety aspect for participants who had memory problems. ○ *“I think it’s because there’s a lot of people who, again, you can get along with. There’re very nice people here, because, like I said, they’ve all had similar problems. You just learn to get on with everybody…it’s just so much like a family, you just get on with everybody. Like me, I can’t remember everybody’s names now, and it’s like a little family, because they’ve all been through the same conditions, all ended up with the same problems. So, I think that’s why you get on so well with everybody. So, it’s just like a little unit, a little family, I think." (page 3408)* • Normality and belonging: Head Forward as a place where personal and social identity can be reconstructed ○ Participants reported that the centre allowed them to socialise with other people with brain injuries, which was important in decreasing people's experience of being abnormal (commonly felt in the outside world) and isolation, and increasing their sense of belonging to a community. People with head injuries were thought to be better able to understand the difficulties faced (for example, cognitive sequalae of the injury or issues with communication). ○ *“Coming here has helped me over the years because I’ve really socialised with a lot of people, and I’ve made a lot of friends…People that have been through the same sort of thing that you’ve been through. And that’s why I find it easier to talk to people, because people outside don’t understand the problems you have. They’ll turn around to me, and because I’m walking and talking… and they think I’m alright… and they don’t know, they don’t know the problems that I do have. And that upsets me sometimes.” (page 3409)*

HRC: Head Forward Centre; N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of recruitment, lack of consideration given to relationship between researcher and participants, lack of discussion regarding credibility, lack of discussion about study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Simpson, 2020

Bibliographic Reference	Simpson, Suzanne; Smith, Sandra; Furlong, Moira; Ireland, Janet; Giebel, Clarissa; Supporting access to activities to enhance well-being and reduce social isolation in people living with motor neurone disease.; Health & social care in the community; 2020; vol. 28 (no. 6); 2282-2289

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK
Setting and aim	**Setting**

	Community based intervention (part of a parent trial investigating the effectiveness of the intervention to support access to meaningful activities within a participant's community. Possible activities were identified, prioritised and risks were assessed before developing a plan for access. Occupational therapists and link workers were involved as much as a participant's activity choices and goals dictated) **Aim** To explore the views of people with motor neurone disease and social prescribing link workers on barriers and facilitators to implementing an intervention to support psychological wellbeing and decrease social isolation.
Data collection and analysis	**Data collection** Method: Interviews. No further details reported. Setting: Not reported Format: Not reported. **Analysis** Thematic analysis. No further details reported.
Recruitment strategy	Participants were recruited by MND Association visitors, public advisors, community therapists and council-based occupational therapists in 2 North West England areas.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People with a confirmed diagnosis of moderate-presenting motor neurone disease (Amyotrophic Lateral Sclerosis Function Rating Scale below 30). ○ People with an Amyotrophic Lateral Sclerosis Function Rating Scale above 30 were judged on a case-by-case basis to determine whether participation in exercise would be appropriate.
Exclusion criteria	• People requiring respiratory support during the day

Sample size	N=9 adults with motor neurone disease plus healthcare professionals
Participant characteristics	**Adults with motor neurone disease, n=5** Age in years [Mean (SD)]*: 56 (SD not reported), age range 40-79 Sex (M/F): n=2/n=3 Time since diagnosis in months [Mean (SD)]*: 13.6 (SD not reported), range 4-28 Chronical neurological disorder category: Progressive neurological disease **Healthcare professionals working with people with motor neurone disease, n=4** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=4 social prescribing link workers *Unclear whether these figures are for the 5 interview participants or the 9 participants included in the full intervention study
Results	Themes as described in paper: • Aids and adaptations ○ People with motor neurone disease noted that the wait for home adaptations had left them unable to leave their homes without a wheelchair. The type of wheelchair affected access to transportation due to various reasonings (for example, issues with dismantling, difficulty lifting, and the need to use a wheelchair to use a taxi plus associated costs). These accessibility issues only increased with time since diagnosis. Professionals reflected that these waits for equipment provision and home adaptations were the most significant barriers to participation. ○ *"I couldn't get out 'cause my legs have gone worse so there's only my dad and my friend who are able to push me in a manual wheelchair and I was issued a wheelchair but it was unsuitable 'cause it couldn't fold. I'm just waiting to get more practice." (page 2285)* • Confidence

	○ Participants reported a decrease of confidence when using their electric wheelchairs, meaning they no longer felt able to go out independently. These participants were reluctant to request help because of their previous levels of independence, and also the fact that they lacked consistent access to support. All respondents noted that overcoming this inconsistent support meant relying on active support from family, friends and volunteers. ○ *“they've lost a lot of confidence and ok, from a practical viewpoint they're waiting for machinery from a confidence viewpoint it's when that machinery comes suddenly that's a whole different ball game of how do I use that, what happens if I go out and the battery runs dead on the wheelchair, er what happens if I come across a ramp or that I can't get up or other issues when I'm out when I haven't anticipated…" (page 2285)* • Stigma ○ Participants reported that accessing community activities was hindered by a lack of awareness of chronic neurological disorders in the general population. Examples included blocking drop down pavements and being unaware of wheelchair users. Link workers reflected that biases and concern about a person's disorder might mean that some social groups and activities outright excluded people with chronic neurological disorders. Participants also reported a variety of barriers to accessing community buildings, including a lack of suitable transport and cuts to funding. All link workers noted that they needed community activities and groups for referring people on, and therefore the need to ensure that these groups were adequately resourced. ○ *“…my partner works at like six in the morning and then when he comes home I can't really expect him to like take me over the water 'cause he wants to go to bed for an hour 'cause he's been up since like five…and my dad's only just got on my car so at the time I couldn't really rely on my partner to like to take me." (page 2285)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of recruitment, data collection, and analysis methods, lack of discussion regarding credibility.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Taylor, 2011

Bibliographic Reference	Taylor, Bridget; The impact of assistive equipment on intimacy and sexual expression; British Journal of Occupational Therapy; 2011; vol. 74 (no. 9); 435-442

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	UK
Setting and aim	**Setting** Rehabilitation services **Aim** To explore the experiences of people with motor neurone disease as well as their feelings about how their condition has impacted their sexual expression and intimacy. To also explore the meaning of sexuality and intimacy and identify recommendations for healthcare professionals.

Data collection and analysis	**Data collection** Method: Conversational interviews. Two interviews held with each participant (3 participants only participated in 1 interview), with the 2nd interview held 2-6 weeks later. Interviews lasted on average 66 minutes. Location: 'Mostly' at home. Format: Face-to-face, audio recorded and transcribed verbatim. Interviews were conducted individually. No topic guide was used. Field notes were kept throughout interviews and analysis. **Analysis** Hermeneutic phenomenological analysis. Transcripts were read and re-read to interpret and identify initial themes. These preliminary themes were confirmed back with the transcripts.
Recruitment strategy	Purposive sampling. Participants were recruited through a specialist motor neurone disease clinic by a specialist nurse. People were given information to take away, and interested parties returned a reply slip.
Study dates	August 2008 - March 2010
Sources of funding	Not industry funded
Inclusion criteria	• Adults attending a specialist motor neurone disease clinic, who were aware their disorder was life-limiting, and able to speak English.
Exclusion criteria	• People unable to provide informed consent. • People who were deemed to be too ill to participate by healthcare professionals.
Sample size	N=23 adults with motor neurone disease plus partners
Participant characteristics	**Adults with motor neurone disease, n=13** Age in years [Mean (SD)]: Not reported, age range 32-82 Sex (M/F): n=8/n=5

	Time since diagnosis: Not reported Chronic neurological disorder category: Progressive neurological disease **Partners of people with motor neurone disease, n=10** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported
Results	Themes as described in paper: • The impact of equipment upon relationships ○ Participants reported that lightwriters affected romantic expressions between partners. Words of affection did not sound individual and did not convey emotion. ○ *"When I want to tell him how much I love him it doesn't sound the same from a machine" (page 438)* • The role of the occupational therapist ○ The majority of respondents reported that they had not had conversations with healthcare professionals about sexuality or intimacy. Occupational therapists were accessed by several participants, but they had not brought up the subject, even during periods of relationship stress such as partners moving into separate bedrooms. One participant could not envision having this sort of conversation with occupational therapists due to a lack of rapport. This led to people being unsure as to what help occupational therapists could offer them. ○ *"An OT [occupational therapist] has never discussed anything other than aids, things that you need like bars to get you off the loo or whatever and things like that. I don't know, I think it would have to be somebody that you felt empathy with to discuss it. I mean I wouldn't sort of want an OT 'cause I mean they can change so often, popping in and saying, 'now I think I'll fit the loo rail' and then 'how's your sex life?'" (page 439)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Poor description of data analysis methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Thrussell, 2018

Bibliographic Reference	Thrussell, Helen; Coggrave, Maureen; Graham, Allison; Gall, Angela; Donald, Michelle; Kulshrestha, Richa; Geddis, Tracey; Women's experiences of sexuality after spinal cord injury: a UK perspective.; Spinal cord; 2018; vol. 56 (no. 11); 1084-1094

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community **Aim** To explore women's experience of sexuality after spinal cord injury, including rehabilitation services and management of the practical aspects.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted on average 55 minutes (ranging 17-143 minutes).

	Location: At home on spinal cord injury centre. Format: Face-to-face, teleconference, or telephone, digitally recorded, and transcribed. **Analysis** Thematic content analysis. Transcripts were uploaded to NVivo software (version not reported) prior to coding by 2 researchers and identification of initial themes, which were then condensed into final themes. Transcriptions were also distributed to the wider research team to identify themes that may have been missed.
Recruitment strategy	Purposive sampling. Participants were recruited from 3 spinal cord injury centres, and chosen to reflect a variety of age, level of spinal cord injury and density of spinal cord injury. Invitations were sent to eligible candidates, with interested people followed up via telephone to determine suitability and enrolment.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• Women with spinal cord injury aged 18 years or older who were experiencing issues with sexual function, were at least 1 year following initial rehabilitation, and who had been sexually active since their injury.
Exclusion criteria	Not reported
Sample size	N=27 adult women with spinal cord injury
Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 21-72 Sex (M/F): n=0/n=27 Time since injury in years [Mean (SD)]: Not reported, range 1-50 Chronic neurological disorder category: Acquired spinal cord injury
Results	Themes as described in paper: • Sexuality rehabilitation

	○ Participants reported a need for female-orientated sexual rehabilitation, as their concerns were very different from the mechanical impairments experienced by many men with spinal cord injury. Women felt as though their sexual rehabilitation needs were often overlooked by healthcare professionals, especially if they were single. Respondents reflected that healthcare professionals did not possess adequate knowledge, were too embarrassed to bring up sexual wellbeing, and were unable to signpost them to relevant information and support services. Participants wanted healthcare professionals to be approachable about sexuality concerns. Particularly, they wanted education to focus less on reproduction and more upon the enjoyment and emotional benefits of sex. ○ Women reported feeling less sexually attractive during rehabilitation, noting the need for support to improve self-confidence, self-esteem, body image and social skills. Women who participated in psychosexual counselling and women-only sexual education sessions reported these to be helpful. Additional interventions to improve sexuality rehabilitation included couples counselling and increased access to peer support. Access to sexual rehabilitation specialists at all post-injury stages was also identified as being helpful. Respondents reflected that sexuality is a highly personal issue that should be addressed accordingly through their rehabilitation. Support needs were expected to change over time, meaning that style and content would need to be flexible. Some participants noted that sexuality was not a priority during rehabilitation, meaning that they later felt as though they had missed out on an opportunity to learn. ○ *"What I found is, it is all centred around men, it’s all centred on their dysfunction and obviously they can’t get an erection and there’s all these toys and gadgets and things for them to do to get the erection. And Viagra and all of that. But when it comes to women, it seems that, well okay you can have sex normally, if you’ve got a willing partner to have sex with. But there is nothing out there that says how to climax […] it can’t be just about men and their sexual dysfunction after a spinal cord injury. It has got to be sort of a joint thing, because women like to have sex as well" (page 1091)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of data collection, and analysis methods, lack of consideration given to relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Tresman, 2016

Bibliographic Reference	Tresman, Rachel; Brown, Morven; Fraser, Faye; Skinner, Roderick; Bailey, Simon; A School Passport as Part of a Protocol to Assist Educational Reintegration After Medulloblastoma Treatment in Childhood.; Pediatric blood & cancer; 2016; vol. 63 (no. 9); 1636-42

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported **Aim** To explore the experiences of parents of children with medulloblastoma plus healthcare and education professionals about return to education after treatment. These views would inform a protocol for reintegration to improve the consistency of support offered.

Data collection and analysis	**Data collection** Method: • Free-text survey questionnaire completed by parents. • Semi-structured interviews for healthcare and education professionals. • Focus groups for healthcare professionals. Location: • Free-text questionnaire for parents: Not applicable. • Semi-structured interviews for healthcare and education professionals: Places of employment. • Focus groups for healthcare professionals: At study hospital. Format: • Free-text questionnaire for parents. Mailed to parents after enrolment in study. Contained free-text questions around parent and child experiences of return to education and inclusion at various stages of recovery and rehabilitation. • Semi-structured interviews for healthcare and education professionals. Interviews lasted between 35-93 minutes. Interviews with education professionals were conducted first and then the interviews with healthcare professionals. • Focus groups for healthcare professionals. Focus groups lasted approximately 1 hour. Conversation focused on discussion of a draft protocol for school reintegration that had been informed by questionnaire and interview results. **Analysis** Thematic analysis. Interviews and focus groups were audio recorded, transcribed verbatim and inputted into NVivo 10 software. All data were analysed together and organised into themes, answering the question of what interventions could improve reintegration to education and development of a finalised protocol.
Recruitment strategy	• Parents of children meeting the criteria were mailed information on the study and invited to participate. • If parents consented, education professionals from schools of the children (either initial school after treatment completion or current school) who had knowledge of the children and parents were invited to participate.

	• Healthcare professionals from the medulloblastoma multidisciplinary team at the study hospital were invited to participate. No further details reported.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criria	• Parents of children who had completed treatment at the Great North Children's Hospital for medulloblastoma. ○ Full psychometric data was available. • Educational professionals working in schools where included children had initially returned to education, or where they were currently attending. • Healthcare professionals working the medulloblastoma multidisciplinary team at the Great North Children's Hospital.
Exclusion criteria	Not reported
Sample size	N=27 parents of children and young people with medulloblastoma plus healthcare and education professionals
Participant characteristics	**Parents of children and young people with medulloblastoma, n=9** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported, median 12.7 Sex of children and young people with chronic neurological disorders (M/F): n=7/n=2 Chronic neurological disorder category: Acquired brain injury **Rehabilitation professionals working with children and young people with medulloblastoma, n=6** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: n=1 clinical psychologist, n=1 consultant paediatric oncologist, n=1 hospital school teacher, n=1 nurse specialist, n=1 occupational therapist, n=1 social worker **Education professionals working with children and young people with medulloblastoma, n=12**

	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism (n): n=5 Special Educational Needs Coordinators, n=2 head of year or previous head of year, n=2 teaching assistants, n=1 ex-class teacher, n=1 Special Educational Needs Coordinator and ex-class teacher, n=1 not reported
Results	Themes as described in paper: • Information sharing: More Information was wanted before return to school ○ Education professionals were unsure about what new needs children might have post-treatment, and believed the early and focused information on these needs was important to ensure that support was in place for when they returned to education. Healthcare professionals reflected that parents were frustrated at the slow pace of support provision. However, they also noted that initial needs might not always be known when children and young people return to education, so there is a practical limit on how soon before this that information could be shared. ○ *"I think there's just often a massive sense of frustration that everything is so slow … seeing their child aware that they're struggling … and them not getting the extra support I think must be horrific" (page 1637)* • Information sharing: Information sharing within schools is challenging ○ Parents and healthcare professionals reported that there can be a lack of information sharing within education settings, meaning that they periodically had to repeat information and explanations (for example, at the beginning of each school year). Sharing information with the correct people within schools also did not always happen. ○ *"You do this big meeting you give them lots of resources, you empower them, you give them lots of support, you go away and then the year after the school ring up and say oh can you come in and do it again…" (page 1638)* • Information sharing: Transition between schools presents multiple issues ○ A main point of information loss on a child's education support needs was during transition between schools. ○ *No first-order quotes to support this theme.*

	• Education and empowerment of the education professional and parents: Empowerment is vital for successful long-term schooling ○ Although it is important to not put parents under undue pressure, parents should be encouraged to advocate for their children and support provision. This could be encouraged by ensuring they know what is expected of different organisations during the process of returning to education. ○ *“For parents and young people to have some control …this is what you should expect, and if it’s not happening, why is that not happening” (page 1639)* • Communication: Hospital–school communication is valued ○ In-person meetings between healthcare professionals and education professionals was noted as being very helpful in facilitating open communication. It allowed time to negotiate the priorities and aims of each individual involved in a child's return to education. Education professionals also appreciated having a named hospital contact where they could direct specific questions and provide support if needed. This could empower education professionals and settings in dealing with certain support needs (for example, transitions between school years or absences). ○ *“It’s about talking to school and negotiating with them about what their priorities are, what your priorities are for treating your tumour, what the kid’s priorities are, what the parents priorities are and what their abilities are, and it’s then balancing those and then having that as a conversation with school really” (page 1639)* • Long-term difficulties: Long-term follow-up ○ Educational settings might not be able to implement long-term information during initial reintegration, due to an overwhelming amount of information. A refresher session later on may help address this. Respondents also commented that a child's long-term education support needs might not be known at the time they return to education, and therefore long-term follow-up was needed to address them as they arise. Healthcare professionals said that they did not receive regular formal communication from education settings, which meant they were not aware of support needs until it was a major issue. ○ *“A refresher …so you can ask questions and go back over it, and you’ll have new questions because now you know what you didn’t know, and you don’t know that at the beginning” (page 1639)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment, data collection, and analysis methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Appendix E Forest plots

Forest plots for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

No meta-analysis was conducted for this review question and so there are no forest plots.

Appendix F GRADE-CERQual tables

GRADE-CERQual tables for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

Access to support for education

Table 5: GRADE-CERQual table for theme K1 Acceptability

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme K1.1: Readiness of schools to engage						
1 study • Bennett 2023 (General qualitative inquiry, acquired brain injury)	Parents and carers of children and young people identified that the school's readiness to engage with the young person's needs affected access to educational support. Practices that worked well include meetings with head teachers, knowing educational professionals were informed about acquired brain injury, and quickly implementing their education care plan. *"feeling safe and supported in school, by staff who are informed and understanding" (page 632, Bennett 2023)*	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW
Sub-theme K1.2: Timeliness of support						
2 studies • Bennett 2023 (General qualitative inquiry, acquired brain injury) • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Parents, healthcare professionals and education professionals reported that the process of getting an education care plan and actioning it took too long, leaving parents feeling frustrated with the lack of education support. Early and focused information about	Moderate concerns (Evidence down-graded due to moderate concerns about methodological	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	educational support needs is important to ensure that support can be put in place as early as possible (ideally before the young person resumes education). *"I think there's just often a massive sense of frustration that everything is so slow … seeing their child aware that they're struggling … and them not getting the extra support I think must be horrific" (page 1637, Tresman 2016)*	limitations as per CASP qualitative checklist)			without rich data)	

Table 6: GRADE-CERQual table for theme K2 Integration (including communication)

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme K2.1: Collaboration between healthcare and education						
2 studies • Bennett 2023 (General qualitative inquiry, acquired brain injury) • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Parents reported that a lack of collaboration between healthcare professionals and education providers led to increased difficulty in accessing support for education. In the worst cases, support needs that had previously been agreed between rehabilitation professionals and education settings were not implemented when children returned to education. In-person meetings between healthcare professionals and education professionals was noted as being very helpful for collaboration, allowing time to negotiate priorities	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	and the aims of each individual involved in the return to education. *"It's about talking to school and negotiating with them about what their priorities are, what your priorities are for treating your tumour, what the kid's priorities are, what the parents priorities are and what their abilities are, and it's then balancing those and then having that as a conversation with school really" (page 1639, Tresman 2016)*					
Sub-theme K2.2: Communication from education to rehabilitation professionals						
2 studies • Bennett 2023 (General qualitative inquiry, acquired brain injury) • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Parents and healthcare professionals wanted education professionals to communicate with rehabilitation teams more. Not only would this allow them to better understand the education support options offered by the NHS but would allow support challenges to be addressed before they became a serious barrier. *"Sometimes you're not prepared when suddenly the whole pack of cards comes tumbling down …so I, you know if I had some more objective feedback (from schools) I might have some idea if …the wheels are coming off really" (page 1639, Tresman 2016)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW
Sub-theme K2.3: Communication from rehabilitation to education professionals						
1 study	Parents and carers reported that communication from healthcare professionals was important for	Moderate concerns	No or very minor concerns	No or very minor concerns	Moderate concerns	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Bennett 2023 (General qualitative inquiry, acquired brain injury)	education staff to understand their role within a child's rehabilitation, take note of recommendations from healthcare professionals, and know what support should be in place for them. This should be maintained throughout rehabilitation and not just at the beginning of the process. *". . . there should have been some direct communication between hospital and school. School knew nothing about what had happened or what should be in place and simply relied on asking us what they needed to do." (page 633, Bennett 2023)*	(Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)			(Evidence downgraded as findings derived from 1 study with rich data)	
Sub-theme K2.4: Named contact						
1 study • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Education professionals reported that it was very helpful to have a named hospital contact where they could direct specific questions and request support. This could empower education professionals in dealing with certain support needs (for example, transitions between school years or absences). *"Sometimes things are ticking along nicely and then there's a hiccup and a bump along the way and, and that might be …when we have a point of contact" (page 1639, Tresman 2016)*	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW
Sub-theme K2.5: Sharing information within education settings						

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 study • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Parents and healthcare professionals reported that there can be a lack of information sharing within education settings, meaning that they periodically had to repeat information and explanations (for example, at the beginning of each school year). It also meant that information was not always shared with the education professional most suitable to provide support. *"You do this big meeting you give them lots of resources, you empower them, you give them lots of support, you go away and then the year after the school ring up and say oh can you come in and do it again…" (page 1638, Tresman 2016)*	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW

Table 7: GRADE-CERQual table for theme K3 Provision of information

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 study • Dunford 2020 (General qualitative inquiry, acquired brain injury)	Children and young people reported a need for increased information about education options, including special schools, possible alternative routes into university, and special adjustments that could be offered in exam situations. *"Having information about special schools and things would just make*	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	you feel more comfortable about school." (page 6, Dunford 2020)					

Table 8: GRADE-CERQual table for theme K4 Sustainability

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme K4.1: Emerging and changing support needs						
1 study • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Parents and carers, healthcare professionals and education professionals pointed out that education support needs may not be known when a young person returns to education so there is a limit to the information that can be shared at this stage. Instead, long-term follow-up is essential to address needs as they arise, as well as deal with changing support needs. *No first-order quotes to support this theme.*	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW
Sub-theme K4.2: Repetition of information						
2 studies • Dunford 2020 (General qualitative inquiry, acquired brain injury) • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Children, young people and education professionals highlighted that information may need to be repeated, especially if a lot of information is given at once (for example, during the initial return to education). Refresher sessions among school staff may be a good way of doing this, particularly for more long-term support needs.	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	"A refresher …so you can ask questions and go back over it, and you'll have new questions because now you know what you didn't know, and you don't know that at the beginning" (page 1639, Tresman 2016)					

Table 9: GRADE-CERQual table for theme K5 Transition

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
2 studies • Bennett 2023 (General qualitative inquiry, acquired brain injury) • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Parents and carers, healthcare and education professionals reported that during the period of transition between schools, information about the young person's needs is often lost, due to a lack of communication between education settings. A way of mitigating against this was for parents to be involved during this time, ensuring that information on education needs and challenges was correctly communicated. *"For secondary school – making sure the right information is handed over from primary school but again I had to request a meeting with safeguarding lead to make sure they were aware of my child's difficulties." (page 633, Bennett 2023)*	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW

Table 10: GRADE-CERQual table for theme K6 Advocacy

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme K6.1: Healthcare professionals as advocates						
2 studies • Bennett 2023 (General qualitative inquiry, acquired brain injury) • Dunford 2020 (General qualitative inquiry, acquired brain injury)	Parents and carers said healthcare professionals were often very helpful in advocating for educational support needs. Children and young people reflected that this could be because professionals were taken more seriously by the school, compared to parents or young people. *"The epilepsy nurse was amazing. She became our voice at school" (page 631, Dunford 2020)*	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW
Sub-theme K6.2: Parents or carers as advocates						
2 studies • Bennett 2023 (General qualitative inquiry, acquired brain injury) • Tresman 2016 (General qualitative inquiry, acquired brain injury)	Parents have an important role advocating for their child's education support needs, ensuring that schools understand their child's new requirements and details such as when they can rejoin certain activities. This was a view shared by parents and healthcare professionals. However it was difficult for parents to advocate when they did not have the proper information about available support options. Their role as advocates could therefore be supported by ensuring parents know what is expected of different organisations during the return to education and enabling open communication with education providers.	Moderate concerns (Evidence down-graded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 2 studies with rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	"Having to ask for support to be put in place but not knowing what can be offered and not being given a choice of different options" (page 630, Bennett 2023)					

Access to support for employment

Table 11: GRADE-CERQual table for theme K7 Acceptability

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme K7.1: Early provision of vocational rehabilitation						
2 studies • De Dios Perez 2022 (Phenomenological, progressive neurological disease) • Hooson 2013 (Phenomenological, acquired brain injury)	People with chronic neurological disorders, healthcare professionals and employers reported that discussions about vocational rehabilitation should begin as early as possible after diagnosis. This raises awareness of what support can be accessed, identifies modifiable environmental factors that may affect employment status, and offers responsive rehabilitation that can be amended as the person's needs change. Returning to work and setting vocational rehabilitation goals can also increase motivation and engagement in other aspects of a person's rehabilitation (for example, physical symptoms or emotional health and wellbeing).	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	"[If I had attended the RTW rehabilitation earlier than I did]…Mmm…Well I think it would have helped me over the initial shock (…) Of realising that the life I had was finished and that there was a new life to go on with…ummm of what, how and when." (page 33, Hooson 2013)					
Sub-theme K7.2: Flexible support						
1 study • De Dios Perez 2022 (Phenomenological, progressive neurological disease)	People with chronic neurological disorders, healthcare professionals and employers reported that flexible support was key in delivering effective vocational rehabilitation and ensuring as many people as possible were able to access support. This could be as simple as signposting to additional resources if support is not readily available, and ensures minimal disruption of the intervention on the lives of people with chronic neurological disorders. A safety net should also be available in order to identify unmet rehabilitation needs and provide early referral to relevant services to address these needs. *No first-order quotes to support this theme.*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	LOW
Sub-theme K7.3: Group settings						
1 study • Hooson 2013 (Phenomenological, acquired brain injury)	People with chronic neurological disorders reported that delivering vocational rehabilitation in group settings encouraged better engagement in the intervention as	Moderate concerns (Evidence downgraded due to moderate	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	they include a social and peer support element. *"We had people that was in the same situation and they seemed to be just getting on with their lives . . . so I thought there's no point just feeling sorry for myself so…come on…buck up and just get on with it…then I found that as I continued with it and tried to move forward then it became easier to keep going forward than sliding back (…) So it was a sort of kick up the backside really." (page 36, Hooson 2013)*	concerns about methodological limitations as per CASP qualitative checklist)			from 1 study without rich data)	
Sub-theme K7.4: Involving employers in rehabilitation						
2 studies • De Dios Perez 2022 (Phenomenological, progressive neurological disease) • De Dios Perez 2023 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	People with chronic neurological disorders reported mixed feelings about including employers in their rehabilitation, as the most common work concerns usually involve managing relationships with employers and colleagues. To mitigate these concerns, people felt it was important for rehabilitation professionals to be able to negotiate and clearly set the expectations of both employers and employees. This ensures that everyone involved understands what is likely to be achieved with vocational rehabilitation and the amount of support required to address the issues and barriers encountered along the way.	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	MODERATE

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	“I was a bit concerned in the early stages about including my employer. Because I feel like I have a supportive employer anyway, I kind of felt that it might be a little bit of a slur on them, that I wanted them included on it.” (page 8, De Dios Perez 2023)					
Sub-theme K7.5: Knowledge of healthcare professionals						
1 study • De Dios Perez 2023 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	People with chronic neurological disorders agreed that when accessing support for employment it’s crucial that healthcare professionals are knowledgeable about vocational rehabilitation (including disorder specific challenges and legal protections). This was supported by the views of healthcare professionals who felt less confident offering employment advice when they lacked this knowledge. *“As doctors, I think it would be very tricky for us to also have that expertise, and be confident enough to deliver those interventions, when it is outside our area of expertise.” (page 7, De Dios Perez 2023)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	LOW
Sub-theme K7.6: Length of rehabilitation intervention						
2 studies • De Dios Perez 2023 (General qualitative inquiry [within mixed-methods study],	People with chronic neurological disorders, healthcare professionals and employers agreed that vocational rehabilitation interventions should last for a longer period of time. This would allow support to encompass applications for government	Moderate concerns (Evidence downgraded due to moderate concerns about methodological	No or very minor concerns	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 2 studies with rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
progressive neurological disease) - Hooson 2013 (Phenomenological, acquired brain injury)	assistance (for example, Access to Work). This continued contact should last as long as needed, to ensure that no further barriers were arising. *"With some things like "Access to Work," the sort of length of time for the study might need to be more flexible so that you start and if things like that have to go back to Government or HR, you can have a sort of a number of hours in one month, and then come back to it." (page 9, De Dios Perez 2023)*	limitations as per CASP qualitative checklist)				
Sub-theme K7.7: Visibility of adjustments						
1 study - Mullin 2018 (Grounded theory, progressive neurological disease)	People with chronic neurological disorders reported that using adaptive equipment that is visible or intrusive in the work environment (for example, voice to text software) made them feel self-conscious about their disability. Instead, they preferred to use equipment with privacy or use alternatives that did not draw attention to their disability. *"Dragon (voice recognition software) will work in a noisy environment but to make it work, I would need to talk more loudly than I normally would do so I feel like a **** reading every punctuation mark to the machine." (page 2036, Mullin 2018)*	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	MODERATE

Table 12: GRADE-CERQual table for theme K8 Availability

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme K8.1: Services to find employment						
1 study • Abbott 2014 (General qualitative inquiry, progressive neurological disease)	People with chronic neurological disorders reported that being offered individualised one-to-one support can help them overcome practical barriers to finding and retaining employment. *No first-order quotes to support this theme.*	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW
Sub-theme K8.2: Support networks within the workplace						
1 study • Mullin 2018 (Grounded theory, progressive neurological disease)	People with chronic neurological disorders reported that formalised internal support networks were very beneficial in supporting them with access to reasonable adjustments and peer support within organisations. However, provision of these were varied. Larger companies were more likely to have pathways in place to support people’s rehabilitation needs, which included a variety of professionals (for example, managers, occupational health, human resources, and disability or union representatives), as well as more likely to implement adaptations correctly. *No first-order quotes to support this theme.*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 1 study with rich data)	LOW

Table 13: GRADE-CERQual table for theme K9 Accessibility

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme K9.1: Bias and assumptions						
3 studies • Abbott 2014 (General qualitative inquiry, progressive neurological disease) • Hoskin 2021 (General qualitative inquiry, progressive neurological disease) • Mullin 2018 (Grounded theory, progressive neurological disease)	People with chronic neurological disorders and their family members reported that their access to support for employment was adversely affected by pre-conceived ideas and assumptions about what individuals would be able to achieve, particularly with regards to long-term employment options. Information either was not provided for individuals, or they were not offered the same level of support or opportunities as other clients. These biases were found among rehabilitation professionals, services to support employment and their own family members. *“I made an appointment to see the Disability Employment Advisor at the job centre, but she wasn’t much good to be honest. She pretty much said straight away that there wouldn’t be any work that I’d be able to do. I was hoping for a bit more of a positive approach than that!” (page 1197, Abbott 2014)*	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 3 studies without rich data)	LOW
Sub-theme K9.2: Line managers as gatekeepers						
2 studies • De Dios Perez 2022 (Phenomenological, progressive neurological disease)	People with chronic neurological disorders, rehabilitation professionals and employers agreed that line managers act as gate keepers when approving reasonable adjustment requests (for example, reducing	No or very minor concerns	Minor concerns (Findings derived from combining themes on positive and	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 2 studies with rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Mullin 2018 (Grounded theory, progressive neurological disease)	working hours, amending physical aspects of a role, or offering the opportunity to work from home), particularly when occupational health or human resource departments were not required to be included. Access to this support could be affected by the manager’s commitment to equality and their relationship with the person making the request. On one hand, people reporting a better relationship with their line manager also reported that their companies were more accommodating of their adjustments. On the other hand, people said their requests were declined or misinterpreted (for example, altering fixed working hours without adding in the flexibility needed to manage fluctuating symptoms) when managers felt that the adjustments would impact how the role would be carried out and potentially shift responsibilities on to other team members. *“A month before I went off sick my manager said that we need to have a chat about hours and working. She said I want you to work 8.30–4.30 and I said I was going to find that a bit tough, you know with the Parkinson’s… How about if I could do flexible, starting from 8, coming in by 9.30 depending on how I am feeling? And that is when she said, ‘No. I want*		negative impacts of line manager relationships)			

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	it done like this and if you are not well enough to come in, you go off sick'" *(page 2036, Mullin 2018)*					
Sub-theme K9.3: Referral from other specialties						
2 studies • De Dios Perez 2022 (Phenomenological, progressive neurological disease) • Hooson 2013 (Phenomenological, acquired brain injury)	People with chronic neurological disorders, rehabilitation professionals and employers suggested that access to support for employment rehabilitation could be improved by including a 'safety net'. This would involve rehabilitation specialists identifying barriers to employment early and referring people on to appropriate services that can offer more specialist advice and support. For example, a speech and language therapist referring an individual for cognitive rehabilitation. *"It did puzzle me for a long time why I had been referred to yourselves and I think what I had boiled down to she [locally based therapist] had recognised subtle symptoms that if they hadn't been treated would probably have left me on a very self-destructive path (. . .) So I consider myself in that respect to be very . . . very lucky . . . that, you know, I didn't slip through the net." (page 35, Hooson 2013)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived from combining themes on safety nets and referral for further rehabilitation)	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW
Sub-theme K9.4: Support from unpaid carers						
1 study	People with chronic neurological disorders acknowledged the importance of unpaid carers in	Moderate concerns	No or very minor concerns	No or very minor concerns	Serious concerns	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
- Hooson 2013 (Phenomenological, acquired brain injury)	supporting them to complete their vocational rehabilitation (for example, by providing transportation or confirming appointments on time). *"Everything I needed. I'd either, if I could do it myself; they'd not do it for me, but assist me in doing it . . . little things like confirming appointments with you . . . I'd forget. My mother would remind me and make sure I'd get on the phone and sort it out with you. And bank issues, eye tests, other doctors' appointments, hospital appointments. She'd take me there because I couldn't get the bus myself. So . . . they ferried me around. I mean, it's all well you offering me appointments in Colwyn Bay. But getting there. I couldn't have done that by myself. So I know there is hospital taxis and transport, but I don't know how reliable they are so . . . yeah, they got me there, took me around, fed me, gave me quite a bit of stability." (page 37, Hooson 2013)*	(Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)			(Evidence downgraded as findings derived from 1 study without rich data)	

Table 14: GRADE-CERQual table for theme K10 Integration (including communication)

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
3 studies - De Dios Perez 2023 (General qualitative	People with chronic neurological disorders, rehabilitation professionals and employers reported on the need for healthcare professionals to	Minor concerns (Evidence downgraded due to minor	No or very minor concerns	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
inquiry [within mixed-methods study], progressive neurological disease) - Hooson 2013 (Phenomenological, acquired brain injury) - Jellie 2014 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	collaborate with other professionals (for example, human resources or legal services) to ensure vocational support is accessed appropriately and implemented successfully. This was identified as not only being important for employment outcomes, but also physical and mental health outcomes. Furthermore, people with chronic neurological disorders felt that having a rehabilitation professional within their workplace helped their rehabilitation needs appear more credible to employers. *“It is just like if somebody else speaks for you a little bit and I think also for my boss to have some sort of official person there. I think for them it was quite good. You know there is not just the patient there is some person from the clinic, just to have a more authoritative figure there.” (page 1597, Jellie 2014)*	concerns about methodological limitations as per CASP qualitative checklist)			from 3 studies without rich data)	

Table 15: GRADE-CERQual table for theme K11 Provision of information

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme K11.1: Available support (including government assistance and legal protection)						
2 studies - Jellie 2014 (General qualitative inquiry [within mixed-methods study],	People with chronic neurological disorders are not always aware of available government assistance (for example, Department of Pensions	No or very minor concerns	Minor concerns (Findings derived from combining	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
progressive neurological disease) - Mullin 2018 (Grounded theory, progressive neurological disease)	'Access to Work' scheme) and legal protections (for example, Disability Discrimination Act [1995]) available to them while in the workforce. Furthermore, they reported receiving conflicting advice on these matters from their employers. When they were educated on the available support, people were more empowered to advocate for themselves and make informed decisions about how they would prefer to manage their disorder within the work environment. *"The main thing was the taxi to work which picks me up in the morning and drops me off at a particular building. I am getting to work fresh during the day obviously it is hard and I have to travel the tube bus and down stairs and in the evening I get the taxi home so that has made a tremendous impact" (page 1596, Jellie 2014)*		themes on different types of available support)		from 2 studies with rich data)	
Sub-theme K11.2: Employment options						
3 studies - Abbott 2014 (General qualitative inquiry, progressive neurological disease) - Hooson 2013 (Phenomenological, acquired brain injury) - Hoskin 2021 (General qualitative inquiry,	People with chronic neurological disorders and their family members said they weren't provided with sufficient information about the work options available to them, including the possibility of self-employment. This lack of information ranged from young people looking to enter employment for the first time, to people who were looking to return to	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 3 studies without rich data)	MODERATE

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
progressive neurological disease)	work following a diagnosis of a chronic neurological disorder. *"[RTW rehabilitation] has shown me there is . . . other avenues . . . as that part of my life last year I just thought that is it . . . It's over. Done with. Never be repeated. But you've [clinicians involved in RTW rehabilitation] shown me that with small steps . . . baby steps, I can keep moving forward and other doors will open for me . . . so there is light at the end of the tunnel." (page 32, Hooson 2013)*					
Sub-theme K11.3: Information for employers						
3 studies • De Dios Perez 2022 (Phenomenological, progressive neurological disease) • De Dios Perez 2023 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) • Mullin 2018 (Grounded theory, progressive neurological disease)	People with chronic neurological disorders, rehabilitation professionals and employers said it was beneficial to engage with employers and colleagues about the potential of vocational rehabilitation for accommodating employees with neurological rehabilitation needs. . Healthcare professionals can support this process of engaging but should be aware that not everyone with a chronic neurological disorder diagnosis wants every aspect of their disease prognosis shared with their employer, as this could lead to discrimination. *No first-order quotes to support this theme.*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived from combining themes on advantages and disadvantages of proving information for employers)	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 3 studies without rich data)	MODERATE

Table 16: GRADE-CERQual table for theme K12 Personalisation of rehabilitation goals

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme K12.1: Experimentation and feedback						
2 studies • Conneeley 2013 (Phenomenological, acquired brain injury) • Mullin 2018 (Grounded theory, progressive neurological disease)	People with chronic neurological disorders, their family members and rehabilitation professionals reported that it is helpful when return-to-work rehabilitation tackled the challenges they would face when reintegrating into the work force. This not only gave opportunities to learn about their current level of abilities and skills, but also develop and practice strategies to adapt their work practices through experimentation and feedback. This can also foster a sense of autonomy and ownership over adaptations, which in turn leads to greater effectiveness when compared to using strategies advised by others. *"Lots of practice building up to his first work assessment. We put the pressure on for him to perform to his utmost and make it as realistic as possible. You know, he wore the clothes and he was quizzed doing it by his boss, he popped in, so I mean there has been so much support for him from his employer, to help him, which has been wonderful." (page 11, Conneeley 2013)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived from combining themes on experimentation with and autonomy over interventions)	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 2 studies with rich data)	MODERATE
Sub-theme K12.2: Setting vocational goals						
2 studies	People with chronic neurological disorders, family members and rehabilitation professionals agreed	Moderate concerns	Minor concerns (Findings derived from	No or very minor concerns	Moderate concerns	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
- Conneeley 2013 (Phenomenological, acquired brain injury) - Hooson 2013 (Phenomenological, acquired brain injury)	that vocational rehabilitation should include realistic and measurable goals to support continued engagement in the process. However, there were concerns that an individual's level of insight and acceptance of limitations might mean setting goals that are too advanced for their current abilities if left to make decisions by themselves, causing further harm. Therefore, rehabilitation professionals need to be able to balance their duty of care while providing and supporting employment opportunities. *"…Looking back with hindsight, if I'd have taken my own course, I hate to think where I would be now. Because I certainly would have gone back to work on a full-time basis, and would certainly have gone back to work to my old job description (…) So it's pretty clear that if I hadn't had goals set by the brain injury unit I would certainly have run the chance of getting back into very…very…serious health problems very quickly" (page 34, Hooson 2013)*	(Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	combining themes on advantages and disadvantages of setting rehabilitation goals)		(Evidence downgraded as findings derived from 2 studies without rich data)	
Sub-theme K12.3: Workplace assessments						
3 studies - De Dios Perez 2023 (General qualitative inquiry [within mixed-methods study],	People with chronic neurological disorders, rehabilitation professionals and employers agreed a detailed workplace assessment is vitally important for identifying needs and implementing the correct strategies to overcome potential barriers to	Minor concerns (Evidence downgraded due to minor concerns about methodological	No or very minor concerns	No or very minor concerns	No or very minor concerns	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
progressive neurological disease) • Hooson 2013 (Phenomenological, acquired brain injury) • Jellie 2014 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	employment. For example, an identified issue with memory and organisational skills may require a cognitive rehabilitation intervention or a fatigue management rehabilitation intervention depending on the cause of the impairment. By completing workplace assessments, rehabilitation professionals also provide an in-person opportunity to support vocational rehabilitation (for example, providing information to employers about an injury, negotiating reasonable adjustments, or advocating for an employee with a chronic neurological disorder). *"I think it was the practical tips really, and talking through them with somebody, it is nice when somebody understands what is going on or says that these things happen, and they are real. It is Ok to feel like that." (page 8, De Dios Perez 2023)*	limitations as per CASP qualitative checklist)				

Access to support for social participation

Table 17: GRADE-CERQual table for theme K13 Acceptability

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme K13.1: Attitudes of other people						
5 studies	Other people's attitudes affect access to support for social participation. This	Moderate concerns	Moderate concerns	No or very minor concerns	No or very minor concerns	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Barrett 2023 (General qualitative injury, acquired spinal cord injury) • Dyer 2014 (General qualitative inquiry, acquired brain injury) • Kelly 2023 (General qualitative inquiry, acquired brain injury) • Learmonth 2013 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) • Simpson 2020 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	finding was based on the views of people with chronic neurological disorders and rehabilitation professionals and opinion was split over whether the impact was generally positive or negative. Positive impacts included healthcare professionals identifying activities people could participate in, assisting them with financial support or checking eligibility criteria of clubs. The attitudes of teachers and other professionals in the community could also provide encouragement for people to try new activities when they were otherwise reluctant. Conversely, when professionals had negative attitudes, for example they were unapproachable in relation to sensitive subject matter, people were less likely to access support for participation. People with chronic neurological disorders also felt discouraged from accessing support if they had concerns about clinical competence or a practitioner’s knowledge of their condition. At worst, activities could be inaccessible because people had not completed the required paperwork (for example, risk assessments) or people with chronic neurological disorders could be excluded from social groups and activities due to discrimination.	(Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	(Findings derived from combining positive and negative attitudes of other people)			

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	"I felt that the individual trainers [in previous exercise experiences], although they were very sympathetic they didn't really have an understanding, they were frightened as well . . . they were sort of saying well you can't do this and you can't do that. I would be like, oh well, I won't go at all." (page 85, Learmonth 2013)					
Sub-theme K13.2: Complex application processes						
1 study • Freeman 2020 (Phenomenological, progressive neurological disease)	People with chronic neurological disorders reported that accessing government payment schemes to support social participation were made difficult due to confusing and bureaucratic application processes. This barrier could be exacerbated by the cognitive symptoms of their disorder. *"..there seem to be so many aspects of it. But you don't realise and you say can you speak to so and so and "no, they're not in today", you know and "she'll ring you when they're next in." And that's probably three weeks later" (page 19, Freeman 2020)*	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	MODERATE
Sub-theme K13.3: Electronic voices						
1 study • Taylor 2011 (Phenomenological, progressive neurological disease)	People with chronic neurological disorders and their partners reported that using electronic assistive equipment could adversely impact intimacy and romantic expressions between partners, because a robotic voice is unable to convey emotions.	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	"When I want to tell him how much I love him it doesn't sound the same from a machine" (page 438, Taylor 2011)	CASP qualitative checklist)			without rich data)	
Sub-theme K13.4: Support in group environments						
7 studies • Barrett 2023 (General qualitative injury, acquired spinal cord injury) • Freeman 2020 (Phenomenological, progressive neurological disease) • Gibbs 2022 (General qualitative inquiry, acquired brain injury) • Hoskin 2021 (General qualitative inquiry, progressive neurological disease) • Jones 2019 (General qualitative inquiry, progressive neurological disease) • Learmonth 2013 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	Evidence was mixed about the role of group settings in enabling access to support for participation. Some people with chronic neurological disorders appreciated condition-specific groups because they provided access to people who understand their disorder and the difficulties encountered during rehabilitation. For some, it was the first time they had met other people with their disorder and this fostered a sense of belonging, emotional support, social cohesion and teamwork, whilst reducing social isolation. People were also glad to feel less noticeable when engaging in physical activities, as other people would be exhibiting similar physical symptoms. On the other hand, people described the ways in which group settings make it difficult to access support for participation. Group delivery seemed inappropriate if there were a wide range of individual needs and requirements within the cohort, or if topics were sensitive in nature. People also reported not having	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived by combining themes on positive and negative aspects of group environments and peer support)	No or very minor concerns	No or very minor concerns	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
- Salas 2021 (General qualitative inquiry, acquired brain injury)	anything in common with attendees beyond their disorder. Finally, people with progressive disorders were mindful of seeing people in more advanced stages of their disease, and of their loved ones seeing the same thing. *“Alfred: I think it’s because there’s a lot of people who, again, you can get along with. There’re very nice people here, because, like I said, they’ve all had similar problems. You just learn to get on with everybody…it’s just so much like a family, you just get on with everybody. Like me, I can’t remember everybody’s names now, and it’s like a little family, because they’ve all been through the same conditions, all ended up with the same problems. So, I think that’s why you get on so well with everybody. So, it’s just like a little unit, a little family, I think." (page 3408, Salas 2021)*					

Table 18: GRADE-CERQual table for theme K14 Availability

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme K14.1: Community activities and groups						
4 studies - Freeman 2020 (Phenomenological,	People with chronic neurological disorders and healthcare professionals reported that access to community activities and groups to	Minor concerns (Evidence downgraded due to minor	Minor concerns (Findings derived by combining	No or very minor concerns	No or very minor concerns	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
progressive neurological disease) • Jones 2019 (General qualitative inquiry, progressive neurological disease) • Learmonth 2013 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) • Simpson 2020 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	promote social participation was hindered by a lack of availability of these services. Reasons for this ranged from geographical barriers (for example, rural areas), poor resources (for example, cuts to funding), or lack of graded exercise or activity options for people with varying abilities due to their disorders (for example, advanced fitness levels required for participation). *“an organisation called XXX so if we speak to people anywhere in Liverpool and they say I've got a disability but I'd really like to join an art group and we think ah XXX will pick you up, but they're under threat of closing and we're thinking that's really going to be such a loss isn't it if it does go.” (page 2285, Simpson 2020)*	concerns about methodological limitations as per CASP qualitative checklist)	themes on physical and organisational factors limiting availability)			
Sub-theme K14.2: Equipment and home adaptations						
2 studies • Kelly 2023 (General qualitative inquiry, acquired brain injury) • Simpson 2020 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	Access to social participation was made difficult by a lack of available equipment and home adaptations. This view was expressed by people with chronic neurological disorders and rehabilitation professionals. They described how people may be unable to leave their home without wheelchairs or may be restricted with their transportation options by the type of wheelchair they need to use. Other examples include venues only offering accessible versions of	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	equipment needed to participate in activities at certain times of day. *“I couldn't get out 'cause my legs have gone worse so there's only my dad and my friend who are able to push me in a manual wheelchair and I was issued a wheelchair but it was unsuitable 'cause it couldn't fold. I'm just waiting to get more practice.” (page 2285, Simpson 2020)*					
Sub-theme K14.3: Inpatient and outpatient sexual rehabilitation						
3 studies • Barrett 2023 (General qualitative injury, acquired spinal cord injury) • Dyer 2014 (General qualitative inquiry, acquired brain injury) • Thrussell 2018 (Phenomenological, acquired spinal cord injury)	A lack of inpatient and outpatient sexual rehabilitation services make it difficult to participate in sexual relationships. This view was shared by people with chronic neurological disorders and rehabilitation professionals. The lack of education and information about sexual rehabilitation led to decreased feelings of sexual preparedness, sexual competence and cognitive understanding. This paucity of services was compounded by a lack of knowledge on the subject among healthcare professionals. Healthcare professionals agreed that they were not aware about which specialist services they could refer people to if the subject of sexual rehabilitation was mentioned. *"P1:1 I mean you might be asking a question with this, you know in this*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 3 studies without rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	area, and erm and then you think what the hell do I do with it (laughs) ((laughter from others)). . .I mean I'm certainly aware that (.) our model is to deal with it ourselves or to refer on. And where do you refer on to?.. . I don't view it ((sexuality)) as being particularly more difficult to address than any of the others, but it's just that issue about not really being sure about where you take it P2:1 I'd agree. Yeah, not thought of it like that before" (page 5, Barrett 2023)					
Sub-theme K14.4: Perceived availability						
1 study • Freeman 2020 (Phenomenological, progressive neurological disease)	People with chronic neurological disorders believed that rehabilitation services were too busy and under resourced to help them with their social isolation and this made it difficult for them to access support. *"They're very busy. I wouldn't expect them to" (page 19, Freeman 2020)*	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	LOW
Sub-theme K14.5: Staff and resources						
5 studies • Abbott 2016 (General qualitative inquiry, progressive neurological disease) • Dyer 2014 (General qualitative inquiry, acquired brain injury) • Freeman 2020 (Phenomenological,	People with chronic neurological disorders and rehabilitation professionals reported that poor availability of resources and staff negatively affect access to social interactions and community participation. Some people reported that they were unable to leave the house due to not receiving enough hours of support. Time and resource pressures within rehabilitation and	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived by combining positive and negative themes on staff and resource availability)	No or very minor concerns	No or very minor concerns	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
progressive neurological disease) • Jarvis 2022 (Case study, progressive neurological disease) • Simpson 2020 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	support services can also lead to certain areas of support being prioritised over social participation. *"P1:3 .. . we're so busy sorting out whether they can walk or talk or-, that we haven't got time a lot of the time. Y'know we-we- And it's almost- almost a luxury isn't it? Cos- ((sighs)) y'know, erm, I mean, does the NHS help you to have sex? (.) I don't know" (page 5, Jarvis 2022)*					

Table 19: GRADE-CERQual table for theme K15 Accessibility

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme K15.1: Discussions on intimacy and sexual well-being						
7 studies • Abbott 2016 (General qualitative inquiry, progressive neurological disease) • Barrett 2022 (General qualitative inquiry, acquired spinal cord injury) • Barrett 2023 (General qualitative injury, acquired spinal cord injury)	Discussions about intimacy and sexual well-being were rarely had, which made it difficult to access support in this area since sexual needs were not captured in rehabilitation plans. This finding was based on the experiences of people with chronic neurological disorders, their partners and rehabilitation professionals. Rehabilitation professionals said they were often reticent about initiating these conversations, citing their own awkwardness or attitude to sexual functioning and satisfaction as well as	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	No or very minor concerns	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Dyer 2014 (General qualitative inquiry, acquired brain injury) • Hoskin 2021 (General qualitative inquiry, progressive neurological disease) • Jarvis 2022 (Case study, progressive neurological disease) • Taylor 2011 (Phenomenological, progressive neurological disease)	a lack of skill and expertise in handling sensitive conversations. A suggestion to strengthen these conversation skills was for professionals to undertake exposure-based training. People with chronic neurological disorders reported being open to having these discussions but were uncertain when and how to raise the topic. They suggested rehabilitation professionals could helpfully provide them with a cue to know when the topic could be discussed, as it does not seem to be part of the standard agenda in rehabilitation planning, assessment or review meetings. *"Participant: . . .it would be good in general, in the care industry, if they thought about these things more. Things about sex, which are important to people. Relationship things. It might be just me, and if I did talk about it, it would be fine. But it has to come from both you and the agencies. It would be valuable. It's quite an important part about being. . . But it's not something they obviously think about at all. If they were more open about it, it might be easier for me to talk to my carers about. Interviewer: So it's never, for example, featured in those planning discussions or. . . Participant: No. Not really, no. It might*					

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	make it easier to be open about it if they were." (page 425, Abbott 2016)					
Sub-theme K15.2: Travel concerns and physical barriers						
6 studies • Abbott 2016 (General qualitative inquiry, progressive neurological disease) • Freeman 2020 (Phenomenological, progressive neurological disease) • Jones 2019 (General qualitative inquiry, progressive neurological disease) • Kelly 2023 (General qualitative inquiry, acquired brain injury) • Learmonth 2013 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) • Simpson 2020 (General qualitative inquiry [within mixed-methods study], progressive neurological disease)	Travel concerns and physical barriers make it difficult to access support for social participation. This opinion was shared by people with chronic neurological disorders and rehabilitation professionals. They agreed that transportation costs and availability (including carers needed to drive them) limited the activities people could participate in. Once at a venue, other concerns included a lack of disabled parking or drop-down curbs on pavements. *“a couple of people said well, if someone could pick me up [I could go] … some of them, the geography just wasn’t going to work.” (page 6, Jones 2019)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived from themes on travel concerns and physical barriers to participation)	No or very minor concerns	No or very minor concerns	MODERATE

Table 20: GRADE-CERQual table for theme K16 Integrating sexual rehabilitation

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
4 studies • Abbott 2016 (General qualitative inquiry, progressive neurological disease) • Barrett 2022 (General qualitative inquiry, acquired spinal cord injury) • Dyer 2014 (General qualitative inquiry, acquired brain injury) • Jarvis 2022 (Case study, progressive neurological disease)	Outcomes regarding sexual functioning and personal relationships were rarely included in standardised assessments, which makes it appear less important than other areas of functioning and leading to it being subsequently overlooked in rehabilitation planning. Including these outcomes in assessment from the beginning of rehabilitation would help to normalise the subject and allow it to integrate better with standard care and other rehabilitation services. This finding is based on the views of people with chronic neurological disorders and rehabilitation professionals. *"I think it needs to become a standardized assessment or discussion like everything else, like are you able to wash and dress? Can you get off the floor if you fall out of your wheelchair? These are the types of regular discussions we have with clients. I don't think we have discussions about sexual function, but we should. It should be standardized across the board." (page 4, Barrett 2022)*	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

Table 21: GRADE-CERQual table for theme K17 Provision of information

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme K17.1: Information about local social activities						
1 study • Abbott 2014 (General qualitative inquiry, progressive neurological disease)	People with chronic neurological disorders, their parents and their family members said they didn't know what social activities were available to them, which made it difficult to participate in the community. *"I go out with my mum for my dinner on a Tuesday. Sometimes I go to bingo. That's about it. We don't know what else there is out there for us." (page 1197, Abbott 2014)*	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW
Sub-theme K17.2: Information for sexual rehabilitation						
3 studies • Barrett 2022 (General qualitative inquiry, acquired spinal cord injury) • Barrett 2023 (General qualitative injury, acquired spinal cord injury) • Dyer 2014 (General qualitative inquiry, acquired brain injury)	People with chronic neurological disorders and rehabilitation professionals agreed the lack of information on sexual rehabilitation makes it difficult to access support on that topic. They suggested that providing specific reading material would make a huge difference, helping people to educate themselves about the options, reflect on their sexual well-being and rehabilitation needs, and broach the topic with healthcare professionals when they feel comfortable. This information should be available throughout inpatient and outpatient rehabilitation. *"I don't think they have had this identified. . . even on the information leaflet, whether we need to give that*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Minor concerns (Evidence downgraded as findings derived from 3 studies without rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	information leaflet about the unit, like our unit and say - look, these are the aspects, but if you want to discuss it, feel free to discuss it. So at least they are empowered to say, this is something they can discuss. . . Because actually the patient, they are not aware they are allowed to discuss that with us" (page 4, Dyer 2014)					

Appendix G Economic evidence study selection

Study selection for: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

No economic searches were undertaken for this qualitative review.

Appendix H Economic evidence tables

Economic evidence tables for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

No economic searches were undertaken for this qualitative review.

Appendix I Economic model

Economic model for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

Excluded qualitative studies

Table 22: Excluded studies and reasons for their exclusion

Study	Reason for exclusion
Aadal, L. and Kirkevold, M. (2011) Integrating situated learning theory and neuropsychological research to facilitate patient participation and learning in traumatic brain injury rehabilitation patients. Brain Injury 25(78): 717-728	- Country Study conducted in Denmark.
Abbott, David and Carpenter, John (2015) "The things that are inside of you are horrible": children and young men with Duchenne Muscular Dystrophy talk about the impact of living with a long-term condition. Child Care in Practice 21(1): 67-77	- Phenomenon of interest Findings relate to experiences of pain and the emotional impact of living with Duchenne's, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Abbott, David and Carpenter, John (2014) 'Wasting precious time': young men with Duchenne muscular dystrophy negotiate the transition to adulthood. Disability and Society 29(8): 1192-1205	- Phenomenon of interest Findings relate to general experiences of living with Duchenne's, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders. Note: There are also some findings relating to transitioning rehabilitation from children's to adults' services. However, this is outside of scope.
Abrahamson, Vanessa, Jensen, Jan, Springett, Kate et al. (2017) Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: a qualitative study. Disability and rehabilitation 39(17): 1683-1694	- Phenomenon of interest Findings relate to transition between in-patient and community settings, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Ahlstrom, Gerd and Wadensten, Barbro (2011) Family members' experiences of personal assistance given to a relative with disabilities. Health and Social Care in the Community 19(6): 645-652	- Country Study conducted in Sweden.
Alford, K., Banerjee, S., Daley, S. et al. (2021) Understanding quality of life in people living with HIV-associated neurocognitive disorder: A qualitative study. HIV Medicine 22(suppl2): 72-73	- Publication type Poster abstract.
Armstrong-Wood, Richard, Messiou, Chrysovalanto, Kite, Amber et al. (2023) Smartphone accessibility: understanding the lived experience of users with cervical spinal cord injuries. Disability and rehabilitation. Assistive technology: 1-12	- Country Mixed countries. Study included participants from the UK, Australia, Canada, Republic of Ireland, Kenya, the US, and others not specified. Results not presented separately for target country.

Study	Reason for exclusion
Atwal, Anita, Giles, Amy, Spiliotopoulou, Georgia et al. (2013) Living with polio and postpolio syndrome in the United Kingdom. Scandinavian journal of caring sciences 27(2): 238-45	- Phenomenon of interest Findings relate to how polio and post-polio syndrome affects everyday life and quality of life, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Baloch, Aysha L (2022) Functional neurological disorder: A faith and cultural perspective. Dissertation Abstracts International: Section B: The Sciences and Engineering 83(7b): no-specified	- Publication type Thesis.
Barclay, Linda, Lentin, Primrose, McDonald, Rachael et al. (2017) Understanding the factors that influence social and community participation as perceived by people with non-traumatic spinal cord injury. The British Journal of Occupational Therapy 80(10): 577-586	- Country Study conducted in Australia.
Barker Alex, B. and et, al (2014) Social identity in people with multiple sclerosis: a meta-synthesis of qualitative research. Social Care and Neurodisability 5(4): 256-267	- Publication date Systematic review with 7/16 published 2010 or later, and 9/16 published pre-2010. Studies published 2010 or later were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Barley, E.; Robinson, S.; Sikorski, J. (2012) Primary-care based participatory rehabilitation: Users' views of a horticultural and arts project. British Journal of General Practice 62(595): e127-e134	- Population Mixed population. Includes participants who are in protocol (people with multiple sclerosis) and out of protocol (people with bipolar disorder, people with depression, people with mixed anxiety and depression, people with psychotic disorder and people with social isolation). Results not presented separately for target population.
Beal, E.M.; Pelser, C.; Coates, P. (2023) Lockdown life - Experiences of partners of individuals with an acquired brain injury during the COVID-19 pandemic: A qualitative study. Brain Impairment 39(17)	- Phenomenon of interest Findings relate to changes in relationships between cohabiting couples during coronavirus and support networks, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Beaulieu, K. (2012) The return to paid work of individuals following a brain injury. Brain Injury 26(45): 359-360	- Publication type Poster abstract.
Beaulieu, Karen (2019) Lived experiences of return to paid work following a brain injury. The British Journal of Occupational Therapy 82(11): 658-665	- Phenomenon of interest Findings relate to general experiences of returning to work after brain injury, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Beauregard, Line and Noreau, Luc (2010) Spouses of persons with spinal cord injury: impact and coping. British Journal of Social Work 40(6): 1945-1959	- Country Study conducted in Canada.

Study	Reason for exclusion
Beckett, V. and Lewthwaite, J. (2018) Development of an information pack to support families with children with Infantile Onset Pompe Disease to go to school. Orphanet Journal of Rare Diseases 13(supplement2)	- Publication type Conference abstract.
Behn, Nicholas, Togher, Leanne, Power, Emma et al. (2015) Experiences from a communication training programme of paid carers in a residential rehabilitation centre for people with traumatic brain injury. Brain Injury 29(1314): 1554-1560	- Phenomenon of interest Findings relate to feedback about a training intervention for paid carers and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Bennett, E., Fletcher, A., Talbot, E. et al. (2022) Communication and Cooperation: Hearing the Voices of Parents to Improve Return to Education After Childhood ABI. Journal of Head Trauma Rehabilitation 37(6): e513	- Publication type Conference abstract.
Bennett, E.; Woolf, E.; Thomas, S. (2022) Acquired Brain Injury in Childhood: The Knowledge, Experience and Training Needs of Special Educational Needs Coordinators in UK Schools. Brain Injury 36(suppl1): 17-18	- Publication type Conference abstract.
Bevan, Stephen and Et, al (2013) Life and employment opportunities of young people with chronic conditions.: 59	- Population People with chronic conditions including inflammatory bowel disease, diabetes and mental health disorders. Not relevant according to protocol population criteria.
Billet, J.P., Levine, A., Markowitz, J. et al. (2020) Executive functioning changes in early huntington's disease: A qualitative research study. Neurotherapeutics 17(1suppl): 31	- Publication type Conference abstract.
Blackburn, M.; Earle, S.; Komaromy, C. (2015) Relationships and sexuality in young adults with life-limiting conditions in England. Archives of Disease in Childhood 100(suppl3): a89	- Publication type Conference abstract.
Bodley-Scott, S.E.M. and Riley, G.A. (2015) How Partners Experience Personality Change after Traumatic Brain Injury-Its Impact on Their Emotions and their Relationship. Brain Impairment 16(3): 205-220	- Phenomenon of interest Findings relate to emotional and behavioural changes following traumatic brain injury and how this affects romantic relationships, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Boylan, A.-M. (2014) Social inclusion following childhood acquired brain injury (ABI): A qualitative exploration. Brain Injury 28(56): 824	- Publication type Conference abstract.
Brehon, Katelyn, MacIsaac, Rob, Bhatia, Zahra et al. (2023) Outcomes of Implementing a Webinar-Based Strategy to Improve Spinal Cord Injury Knowledge and Community Building: Convergent Mixed Methods Study. JMIR rehabilitation and assistive technologies 10: e46575	- Country Study conducted in Canada.
Brooks, Rob, Lambert, Charlotte, Coulthard, Laura et al. (2021) Social participation to support	- Population Children with neurodisabilities (including autism spectrum disorder, attention deficit hyperactivity

Study	Reason for exclusion
good mental health in neurodisability. Child: Care, Health and Development 47(5): 675-684	disorder, Down syndrome, cerebral palsy and epilepsy). Not relevant according to protocol population criteria.
Brunner, Melissa, Hemsley, Bronwyn, Palmer, Stuart et al. (2015) Review of the literature on the use of social media by people with traumatic brain injury (TBI). Disability and rehabilitation 37(17): 1511-21	- Study design Systematic review with 6/16 qualitative studies, 1/16 systematic review, 7/16 conference abstracts, 1/16 non-systematic literature review, and 1/16 thesis. Qualitative studies and systematic review were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Buckeridge, Katherine; Clarke, Channine; Sellers, Diane (2020) Adolescents' experiences of communication following acquired brain injury. International journal of language & communication disorders 55(1): 97-109	- Phenomenon of interest Findings relate to the barriers and facilitators of communication in classrooms, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Carreon, R.P., Hayes, J.A., Deehan, D. et al. (2021) 'Where do we go from here?': A meta-synthesis of qualitative literature examining the lived experience of Huntington's disease. Journal of Neurology, Neurosurgery and Psychiatry 92(suppl1): a21-a22	- Publication type Conference abstract.
Caute, A.; Mangialardi, E.; Kay, A. (2023) Aphasia iCafe interview project: Student-delivered online social support groups for people with aphasia and/or dysarthria- a qualitative investigation of group members' and providers' experiences. International Journal of Stroke 18(1supplement): 22	- Publication type Conference abstract.
Chan, C.T. and Garikipati, K.K. (2023) Factors associated with physical activity and exercise participation in people with multiple sclerosis: a qualitative systematic review. European Journal of Physiotherapy	- Country Systematic review with 7/39 of the included studies conducted in the UK, 17/39 in the US, 8/39 in New Zealand, 5/39 in Canada, 3/39 in Australia, and 2/39 in Republic of Ireland. UK studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Cheung, L.L.T., Wakefield, C.E., Ellis, S.J. et al. (2014) Neuropsychology reports for childhood brain tumor survivors: Implementation of recommendations at home and school. Pediatric Blood and Cancer 61(6): 1080-1087	- Country Study conducted in Canada.
Chiong-Rivero, Horacio, Ryan, Gery W, Flippen, Charles et al. (2011) Patients' and caregivers' experiences of the impact of Parkinson's disease on health status. Patient related outcome measures 2011(2): 57-70	- Country Study conducted in the US.
Christie, Nicola, Braaf, Sandra, Ameratunga, Shanthi et al. (2017) The role of social networks in supporting the travel needs of people after	- Country Study conducted in Australia.

Study	Reason for exclusion
serious traumatic injury: A nested qualitative study. Journal of Transport & Health 6: 84-92	
Coenen, Michaela, Cabello, Maria, Umlauf, Silvia et al. (2016) Psychosocial difficulties from the perspective of persons with neuropsychiatric disorders. Disability and rehabilitation 38(12): 1134-45	- Country Study conducted in Finland, Italy, Germany, Poland and Spain.
Conneeley, L. (2012) Transitions and traumatic brain injury: Exploring the journey through the first 12 months following discharge to the home. Brain Injury 26(45): 330-331	- Publication type Conference abstract.
Conneeley, L. (2012) Returning to work following traumatic brain injury: Exploring the experince of the journey. Brain Injury 26(45): 332	- Publication type Conference abstract.
Cutler, Melissa and et, al (2016) Mindful connections: the role of a peer support group on the psychosocial adjustment for adults recovering from brain injury. Journal of Social Work in Disability and Rehabilitation 15(34): 260-284	- Country Study conducted in Canada.
D'Cruz, Kate, Douglas, Jacinta, Serry, Tanya et al. (2020) Sharing stories of lived experience: A qualitative analysis of the intersection of experiences between storytellers with acquired brain injury and storytelling facilitators. The British Journal of Occupational Therapy 83(9): 576-584	- Country Study conducted in Australia.
Dalemans, Ruth J. P, de Witte, Luc, Wade, Derick et al. (2010) Social participation through the eyes of people with aphasia. International Journal of Language & Communication Disorders 45(5): 537-550	- Country Study conducted in the Netherlands.
Davison, G., Aldridge, J., Manning, S. et al. (2011) A qualitative study exploring the impact on social well-being of young people living with a life-limiting neuromuscular disease. Developmental Medicine and Child Neurology 53(suppl1): 43	- Publication type Poster abstract.
De Hope, E. and Finegan, J. (2010) The use of relationship meetings to overcome social awareness issues resulting from TBI. Brain Injury 24(3): 263-264	- Publication type Conference abstract.
Dennett, Rachel; Gunn, Hilary; Freeman, Jennifer A (2018) Effectiveness of and User Experience With Web-Based Interventions in Increasing Physical Activity Levels in People With Multiple Sclerosis: A Systematic Review. Physical therapy 98(8): 679-690	- Country Systematic review with 8/9 of the included studies conducted in the US and 1/9 conducted in Germany. No studies checked against protocol criteria as did not include any studies conducted in target country.
Dennison, Laura, Yardley, Lucy, Devereux, Angela et al. (2011) Experiences of adjusting to early stage Multiple Sclerosis. Journal of health psychology 16(3): 478-88	- Phenomenon of interest Findings relate to adjustment and practical strategies to maintain activities of daily living, and not what works well or does not work in accessing support for education, employment,

Study	Reason for exclusion
	and social participation for people with chronic neurological disorders.
Desborough, Jane and et, al (2020) 'It struck at the heart of who I thought I was': a meta-synthesis of the qualitative literature examining the experiences of people with multiple sclerosis. Health Expectations 23(5): 1007-1027	- Country Systematic review with 18/77 of the included studies conducted in the UK, 13/77 in the US, 10/77 in Iran, 6/77 in Australia, 4/77 in Canada, 3/77 in Denmark, 3/77 in the Netherlands, 3/77 in New Zealand, 3/77 in Norway, 3/77 in Sweden, 2/77 in Italy, 2/77 in Japan, 1/77 in Germany, 1/77 in Portugal, 1/77 in Republic of Ireland, 1/77 in Malaysia, 1/77 in South Africa, 1/77 in Turkey, 1/77 in the US and Canada, and 1/77 in Australia and New Zealand. UK studies were checked against protocol criteria – 1 was identified as potentially relevant and retrieved for further screening.
Dickson, Adele, Ward, Richard, O'Brien, Grainne et al. (2011) Difficulties adjusting to post-discharge life following a spinal cord injury: an interpretative phenomenological analysis. Psychology, health & medicine 16(4): 463-74	- Phenomenon of interest Findings relate to experiences of psychological needs and adjustment post-discharge from an acute setting, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Donnelly, Kyla Z; Goldberg, Shari; Fournier, Debra (2020) A qualitative study of LoveYourBrain Yoga: a group-based yoga with psychoeducation intervention to facilitate community integration for people with traumatic brain injury and their caregivers. Disability and rehabilitation 42(17): 2482-2491	- Country Study conducted in the US.
Douglas, J. (2012) Developing and maintaining a sense of connection between the self and society after severe traumatic brain injury. Brain Injury 26(45): 603	- Publication type Conference abstract.
Douglas, J. (2011) The things that help: Developing and maintaining a sense of connection between the self and society after severe traumatic brain injury. Brain Impairment 12(suppl1): 66	- Publication type Conference abstract.
Dunne, Stephen, Williams, Glenn P, Bradbury, Chloe et al. (2023) Uncovering the social determinants of brain injury rehabilitation. Journal of health psychology: 13591053231166263	- Phenomenon of interest Findings relate to social isolation during coronavirus, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Earle, S. and Blackburn, M. (2021) Young adults with life-limiting or life-threatening conditions: Sexuality and relationships support. BMJ Supportive and Palliative Care 11(2): 163-169	- Phenomenon of interest Findings relate to sexuality, the importance of sex in relationships, and ideas for practical support with relationships, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Earle, S., O'Dell, L., Davies, A. et al. (2020) Views and Experiences of Sex, Sexuality and Relationships Following Spinal Cord Injury: A	- Country Systematic review with 3/27 of the included studies conducted in the UK, 9/27 in the US,

Study	Reason for exclusion
Systematic Review and Narrative Synthesis of the Qualitative Literature. Sexuality and Disability 38(4): 567-595	4/27 in Australia, 2/27 in Greece, 2/27 in Iran, 1/27 in Canada, 1/27 in China, 1/27 in Hong Kong, 1/27 in India, 1/27 in South Africa, 1/27 in Sweden, and 1/27 in multiple countries. UK studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Eglseder, Kate and Demchick, Barbara (2017) Sexuality and spinal cord injury: The lived experiences of intimate partners. OTJR: Occupation, Participation and Health 37(3): 125-131	- Country Study conducted in the US.
Flaherty, L., Girgis, C., DiGasbarro, D. et al. (2020) Perceived stigma in patients with functional movement disorder: A qualitative study. Movement Disorders 35(suppl1): 559	- Publication type Conference abstract.
Flynn, Allyson, Dennis, Sarah, Preston, Elisabeth et al. (2022) Exercising with Parkinson's: The good, the bad and the need for support to keep exercising. A qualitative study. Clinical rehabilitation 36(10): 1332-1341	- Country Study conducted in Australia.
Friary, Philippa and et, al (2018) Navigating interprofessional spaces: experiences of clients living with Parkinson's disease, students and clinical educators. Journal of Interprofessional Care 32(3): 303-312	- Country Study conducted in New Zealand.
Gaintza, Zurine, Ozerinjauregi, Nagore, Arostegui, Igone et al. (2018) Educational inclusion of students with rare diseases: Schooling students with spina bifida. British Journal of Learning Disabilities 46(4): 250-257	- Country Study conducted in Spain.
Galushko, M., Golla, H., Strupp, J. et al. (2014) Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: A qualitative study. Journal of Palliative Medicine 17(3): 274-281	- Country Study conducted in Germany.
Gaskill, A.; Bonas, S.; Bennett, E. (2015) Adolescent girls-experiences of school following treatment for a brain tumour: An interpretative phenomenological analysis approach. Neuro-Oncology 17(suppl8): viii19	- Publication type Conference abstract.
Gauvin-Lepage, J. and Lefebvre, H. (2010) Social inclusion of persons with moderate head injuries: The points of view of adolescents with brain injuries, their parents and professionals. Brain Injury 24(9): 1087-1097	- Phenomenon of interest Findings relate to how traumatic brain injury can limit social and emotional participation, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Gerritzen, Esther Vera, Lee, Abigail Rebecca, McDermott, Orii et al. (2022) Online Peer Support for People With Parkinson Disease: Narrative Synthesis Systematic Review. JMIR aging 5(3): e35425	- Country Systematic review with 1/8 of the included studies conducted in the UK, 4/8 in the US, and 3/8 in unspecified countries. UK study was checked against protocol and was either not

Study	Reason for exclusion
	relevant or had been separately located by the literature search and screened.
Gerritzen, Esther Vera, Lee, Abigail Rebecca, McDermott, Orii et al. (2022) Online Peer Support for People With Multiple Sclerosis: A Narrative Synthesis Systematic Review. International journal of MS care 24(6): 252-259	- Country Systematic review with 2/10 of the included studies conducted in the US, 1/10 in Australia, 1/10 in Iran, 1/10 in Italy, 1/10 in South Africa, 1/10 in multiple countries, and 3/10 in unspecified countries. Therefore no studies were checked against protocol.
Glazer, Daniel; Daniilidi, Xeni; Valentino, Charlotte (2022) The development of a cognitive rehabilitation and psycho-social group programme for teenage and young adult survivors of brain tumours: A feasibility study. Clinical child psychology and psychiatry 27(2): 327-335	- Phenomenon of interest Findings relate to feedback about a cognitive rehabilitation and psychosocial group programme intervention, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Glennon, Ciara, Watson, Suzanna, Fisher, Paul et al. (2022) The process of identity change following ABI from the perspectives of adolescents and their mothers: A relational grounded theory approach. Neuropsychological rehabilitation 32(8): 1904-1927	- Phenomenon of interest Findings relate to experiences of changes in identity following brain injury, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Godwin, E.; Chappell, B.; Kreutzer, J. (2014) Relationships after TBI: A grounded research study. Brain Injury 28(4): 398-413	- Country Study conducted in the US.
Goodenough, Trudy; Pease, Anna; Williams, Cathy (2021) Bridging the Gap: Parent and Child Perspectives of Living With Cerebral Visual Impairments. Frontiers in human neuroscience 15: 689683	- Population Unclear population. Children with cerebral visual impairments, with no description of aetiology.
Grayson, Lynn, Brady, Marian C, Togher, Leanne et al. (2020) A survey of cognitive-communication difficulties following TBI: are families receiving the training and support they need?. International journal of language & communication disorders 55(5): 712-723	- Phenomenon of interest Findings relate to cognitive–communication needs, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Griffiths, H C; Clinpsy, D; Kennedy, P (2012) Continuing with life as normal:: positive psychological outcomes following spinal cord injury. Topics in spinal cord injury rehabilitation 18(3): 241-52	- Phenomenon of interest Findings relate to experiences of positive psychological outcomes after injury and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Guay, Martine (2018) Impact of group art therapy on the quality of life for acquired brain injury survivors. Art Therapy 35(3): 156-164	- Country Study conducted in Canada.
Hamana, Katy, Quinn, Lori, Gambling, Tina et al. (2021) An exploration of physical activity experiences throughout the Huntington's disease journey: supporting development of theoretically underpinned complex interventions. Disability and rehabilitation 43(11): 1565-1575	- Phenomenon of interest Findings relate to experiences with modifying and achieving physical activity participation, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.

Study	Reason for exclusion
Hamlet, Claire, Williamson, Heidi, Hotton, Matthew et al. (2021) 'Your face freezes and so does your life': A qualitative exploration of adults' psychosocial experiences of living with acquired facial palsy. British Journal of Health Psychology 26(3): 977-994	- Population People with facial palsy. Not relevant according to protocol population criteria.
Hammill, Kathrine, Stewart, Catherine G, Kosic, Natasha et al. (2019) Exploring the impact of brain cancer on people and their participation. The British Journal of Occupational Therapy 82(3): 162-169	- Country Study conducted in Australia.
Harnett, A., Mehta, S., Cao, P. et al. (2022) The Lived Experience of Pain Following a Spinal Cord Injury: A Qualitative Thematic Analysis. Archives of Physical Medicine and Rehabilitation 103(12): e199-e200	- Publication type Poster abstract.
Hartley, Sandra Elaine; Goodwin, Peter Charles; Goldbart, Juliet (2011) Experiences of attendance at a neuromuscular centre: perceptions of adults with neuromuscular disorders. Disability and rehabilitation 33(12): 1022-32	- Phenomenon of interest Findings relate to the advantages and disadvantages of attending a neuromuscular centre, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Hendrie, W., Dennett, R., Jarrett, L. et al. (2019) "I'm in a very good frame of mind": the experience of standing frame use in people with progressive multiple sclerosis. Physiotherapy (United Kingdom) 105(supplement1): e37	- Publication type Conference abstract.
Ho, A K and Hocaoglu, M B (2011) Impact of Huntington's across the entire disease spectrum: the phases and stages of disease from the patient perspective. Clinical genetics 80(3): 235-9	- Phenomenon of interest Findings relate to the negative impact of disease on everyday life, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Hoffman, Rhianne; Spencer, Elizabeth; Steel, Joanne (2023) A qualitative exploration of speech-language pathologists' approaches in treating spoken discourse post-traumatic brain injury. International journal of language & communication disorders	- Country Mixed countries. Study includes rehabilitation professionals from UK, Australia and the US. Results not presented separately for target country.
Horton, Simon, Humby, Kate, Jerosch-Herold, Christina et al. (2020) Development and preliminary validation of a patient-reported outcome measure for conversation partner schemes: The Conversation and Communication Questionnaire for People with Aphasia (CCQA). Aphasiology 34(9): 1112-1137	- Population Mixed population. Includes adults with aphasia after stroke (proportions not reported). Results not presented separately for target population.
Hughes, Melanie, Burton, Amy E, Dempsey, Robert C et al. (2019) 'I am free in my wheelchair but pain does have a say in it though': The meaning and experience of quality of life when living with paraplegia and chronic pain. Journal of Health Psychology 24(10): 1356-1367	- Phenomenon of interest Findings relate to the impact of wheelchair use on quality of life and pain management, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.

Study	Reason for exclusion
Jackson, Katherine, Hamilton, Sharon, Jones, Susan et al. (2019) Patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition: a qualitative systematic review and meta-aggregation. Disability and rehabilitation 41(23): 2731-2749	- Country Systematic review with 11/37 of the included studies conducted in the UK, 12/37 in Australia, 5/37 in Canada, 2/27 in the US, 2/37 in Republic of Ireland, 1/27 in the Netherlands, 1/27 in New Zealand, 1/27 in South Africa, 1/27 in Sweden, and 1/27 on Norway and Denmark. UK studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Keeble, R., Newton, K., McArthur, S. et al. (2016) INNOVATIVE DAY SERVICES OFFER MORE PEOPLE MORE THAN TEA. BMJ Supportive and Palliative Care 6(supplement1): a79-a80	- Publication type Conference abstract.
Keetley, R., Manning, J.C., Williams, J. et al. (2022) Enabling Participation in Children and Young People With Acquired Brain Injuries and Their Families-A Mixed-Methods Study-Preliminary Results. Journal of Head Trauma Rehabilitation 37(6): e518-e519	- Publication type Conference abstract.
Keightley, M., Kendall, V., Jang, S.-H. et al. (2011) From health care to home community: An Aboriginal community-based ABI transition strategy. Brain Injury 25(2): 142-152	- Country Study conducted in Canada.
Kelly, Helen, Kennedy, Fiona, Britton, Hannah et al. (2016) Narrowing the "digital divide": Facilitating access to computer technology to enhance the lives of those with aphasia: A feasibility study. Aphasiology 30(23): 133-163	- Population Adults with post-stroke aphasia. Not relevant according to protocol population criteria.
Kennedy, P, Sherlock, O, McClelland, M et al. (2010) A multi-centre study of the community needs of people with spinal cord injuries: the first 18 months. Spinal cord 48(1): 15-20	- Study design Limited to quantitative data analysis and reporting.
Kennedy-Behr, Ann and Hatchett, Mikaela (2017) Wellbeing and engagement in occupation for people with Parkinson's disease. The British Journal of Occupational Therapy 80(12): 745-751	- Country Study conducted in Australia.
Kersten, P., Cummins, C., Kayes, N. et al. (2018) Making sense of recovery after traumatic brain injury through a peer mentoring intervention: A qualitative exploration. BMJ Open 8(10): e020672	- Country Study conducted in New Zealand.
Kho, P.B., Anderson, V., Catroppa, C. et al. (2015) Adjustment in life after traumatic brain injury: The impact of cognition, employment, and perceived sense of purpose in life. Journal of Head Trauma Rehabilitation 30(3): e63	- Publication type Conference abstract.
Kirk, S. and Hinton, D. (2015) Childhood multiple sclerosis: An examination of families experiences, support needs and current service models in the uk. Archives of Disease in Childhood 100(suppl3): a7-a8	- Publication type Conference abstract.

Study	Reason for exclusion
Kola, S.; Turner, J.; Dhingra, K. (2015) Challenging lives: An exploratory qualitative study of Quality of life in young adults living with a chronic neurological condition. International Journal of Developmental Disabilities 61(3): 156-165	- Population People with dyslexia, epilepsy, and/or cerebral palsy. Not relevant according to protocol population criteria.
Kolehmainen, Niina, Ramsay, Craig, McKee, Lorna et al. (2015) Participation in Physical Play and Leisure in Children With Motor Impairments: Mixed-Methods Study to Generate Evidence for Developing an Intervention. Physical therapy 95(10): 1374-86	- Phenomenon of interest Findings relate to identifying clinical predictors of participation in physical play and leisure, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Kusec, Andrea, Panday, Janelle, Froese, Amanda et al. (2020) Getting motivated: Long-term perspectives on engaging in community-based programs after acquired brain injury. Brain Injury 34(10): 1331-1338	- Phenomenon of interest Findings relate to engagement in community-based rehabilitation programmes, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Lape, E.C., Katz, J.N., Losina, E. et al. (2018) Participant-Reported Benefits of Involvement in an Adaptive Sports Program: A Qualitative Study. PM and R 10(5): 507-515	- Country Study conducted in the US.
Libeson, Lauren, Ross, Pamela, Downing, Marina et al. (2022) The experience of employers of individuals with traumatic brain injury. Neuropsychological Rehabilitation 32(10): 2580-2602	- Country Study conducted in Australia.
Lorenz, Laura S, Charrette, Ann L, O'Neil-Pirozzi, Therese M et al. (2018) Healthy body, healthy mind: A mixed methods study of outcomes, barriers and supports for exercise by people who have chronic moderate-to-severe acquired brain injury. Disability and health journal 11(1): 70-78	- Country Study conducted in the US.
Lovatt, M.; Ellis, J.; Bath, P. (2016) Empathy, sharing, and support among users of a forum for people with MND. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration 17(supplement1): 306-307	- Publication type Conference abstract.
Lowe, Niamh, Crawley, Lorraine, Wilson, Charlotte et al. (2021) 'Lonely in my head': The experiences of loneliness in individuals with brain injury. British journal of health psychology 26(2): 444-463	- Country Study conducted in Republic of Ireland.
Mackenzie, Catherine, Bennett, Amanda, Cairney, Melissa et al. (2011) Active citizenship and acquired neurological communication difficulty. Disability and Rehabilitation: An International, Multidisciplinary Journal 33(3): 187-194	- Population Mixed population. Includes participants who are in protocol (people with Parkinson's disease) and out of protocol (adults with aphasia after stroke and people with dementia). Results not presented separately for target population.
Malcolm, Lorna, Mein, Gill, Jones, Alison et al. (2016) Strength in numbers: patient experiences	- Population Mixed population. Includes participants who are in protocol (people with motor neurone disease)

Study	Reason for exclusion
of group exercise within hospice palliative care. BMC palliative care 15(1): 97	and out of protocol (people with cancer and people with respiratory diseases). Results not presented separately for target population.
Margetts, K. (2018) THE NEUROLOGICAL HUB. BMJ Supportive and Palliative Care 8(supplement2): a72	- Publication type Conference abstract.
Martin Ginis, Kathleen A, Papathomas, Anthony, Perrier, Marie-Josee et al. (2017) Psychosocial factors associated with physical activity in ambulatory and manual wheelchair users with spinal cord injury: a mixed-methods study. Disability and rehabilitation 39(2): 187-192	- Country Study conducted in Canada.
McGarry, P. and Welk, B. (2018) The bladder management experiences of spinal cord injury patients: A systematic review of qualitative studies. Canadian Urological Association Journal 12(6supplement2): 116	- Publication type Conference abstract.
McGinnis, P., Barile, M., Kilgallen, J. et al. (2011) Community-based wellness program for individuals with parkinson's disease. Physiotherapy (United Kingdom) 97(suppl1): es785	- Publication type Poster abstract.
McGuckin, Matthew E, Law, Barbi, McAuliffe, Jim et al. (2016) Social influences on Return to Play following concussion in female competitive youth ice hockey players. Journal of Sport Behavior 39(4): 426-445	- Country Study conducted in Canada.
Mclean, Craig; Mclean, Liam; Abbott, David (2010) Becoming a man: life with Duchenne muscular dystrophy.: 14p	- Publication type Booklet.
McMaugh, Anne (2011) En/countering disablement in school life in Australia: children talk about peer relations and living with illness and disability. Disability and Society 26(7): 853-866	- Population Mixed population. Includes participants who are in protocol (children with traumatic brain injury) and out of protocol (children with spina bifida, children with cerebral palsy, children with cystic fibrosis and children with other conditions that may have included prolonged periods of illness or hospitalisation). Results not presented separately for target population.
McWilliams, Andrew, Reilly, Colin, McFarlane, Fiona A et al. (2016) Nonepileptic seizures in the pediatric population: A qualitative study of patient and family experiences. Epilepsy & behavior : E&B 59: 128-36	- Phenomenon of interest Findings relate to general experiences of living with nonepileptic seizures, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Meade, Oonagh, Buchanan, Heather, Coulson, Neil et al. (2018) The use of an online support group for neuromuscular disorders: A thematic analysis of message postings. Disability and Rehabilitation: An International, Multidisciplinary Journal 40(19): 2300-2310	- Country Unclear. Online study with data analysed across the UK but no information on geographical location of respondents.
Morgan, Andrew; Eccles, Fiona J R; Greasley, Pete (2021) Experiences of living with dystonia. Disability and rehabilitation 43(7): 944-952	- Phenomenon of interest Findings relate to diagnosis of dystonia, social isolation, and attitudes to psychological causes of symptoms, and not what works well or does

Study	Reason for exclusion
	not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Muldoon, Orla T, Walsh, R. Stephen, Curtain, Mariah et al. (2019) Social cure and social curse: Social identity resources and adjustment to acquired brain injury. European Journal of Social Psychology 49(6): 1272-1282	- Country Study conducted in the Republic of Ireland.
Munro, J. and Gentleman, D. (2010) Relationships between partners after acquired brain injury. Brain Injury 24(3): 242-243	- Publication type Conference abstract.
Naisby, Jenni, Wilson-Menzfeld, Gemma, Baker, Katherine et al. (2023) Yoga and Multiple Sclerosis: Maintaining engagement in physical activity. PloS one 18(7): e0288319	- Phenomenon of interest Findings relate to reasons for participating in, flexibility of, and psychological impact of yoga, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Ness, Bryan M, Rocke, Maya R, Harrist, Christopher J et al. (2014) College and combat trauma: An insider's perspective of the post-secondary education experience shared by service members managing neurobehavioral symptoms. NeuroRehabilitation 35(1): 147-158	- Country Study conducted in the US.
Newton, G.; Griffith, A.; Soundy, A. (2020) The experience of fatigue in neurological patients with Multiple Sclerosis: a thematic synthesis. Physiotherapy (United Kingdom) 107: 306-316	- Country Systematic review with 1/9 of the included studies conducted in the UK, 2/9 in New Zealand, 2/9 in Sweden, 2/9 in the US, 1/9 in Germany, and 1/9 in Japan. UK study was checked against protocol and was either not relevant or had been separately located by the literature search and screened.
Nicklin, E., Phang, I., Short, S. et al. (2022) RETURNING TO WORK AFTER A BRAIN TUMOUR - 'I THOUGHT I WOULD BE BACK AT WORK THE NEXT WEEK, HOW WRONG I WAS!'. Neuro-Oncology 24(supplement7): vii245	- Publication type Conference abstract.
Nicklin, E., Velikova, G., Glaser, A. et al. (2021) Supportive care needs of tya childhood brain tumour survivors and their caregivers: A mixed methods study. Neuro-Oncology 23(suppl2): ii14	- Publication type Conference abstract.
Nicklin, Emma, Pointon, Lucy, Glaser, Adam et al. (2021) Unmet support needs in teenage and young adult childhood brain tumour survivors and their caregivers: "it's all the aftermath, and then you're forgotten about". Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer 29(11): 6315-6324	- Phenomenon of interest Findings relate to experiences with general support services, transitioning to adult services and long-term hospital-based follow-up care, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Olofsson, Alexandra, Nyman, Anneli, Lund, Maria Larsson et al. (2017) Occupations outside the home: Experiences of people with acquired brain injury. The British Journal of Occupational Therapy 80(8): 486-493	- Country Study conducted in Sweden.

Study	Reason for exclusion
Osborne, Jake B, Rocchi, Meredith A, McBride, Christopher B et al. (2023) Couples' experiences with sexuality after spinal cord injury. Disability and Rehabilitation: An International, Multidisciplinary Journal 45(4): 664-672	- Country Study conducted in Canada.
Patel, Chirag M; Ferner, Ros; Grunfeld, Elizabeth A (2011) A qualitative study of the impact of living with neurofibromatosis type 2. Psychology, health & medicine 16(1): 19-28	- Phenomenon of interest Findings relate to physical and emotional impact of the disease and lack of awareness of disorder, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Perepezko, Kate and et, al (2019) Social role functioning in Parkinson's disease: a mixed-methods systematic review. International Journal of Geriatric Psychiatry 34(8): 1128-1138	- Study design Systematic review with 23/51 qualitative studies, 4/51 mixed-methods, and 24/51 primarily quantitative studies. Qualitative and mixed-methods studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Pieridi, C.; Brown, D.; Sterr, A. (2012) The experience of returning to work following a traumatic brain injury. Brain Injury 26(45): 625	- Publication type Conference abstract.
Powell, P. and Carlton, J. (2019) "Social interaction (.) without that then I would probably be miserable": Understanding quality of life in Duchenne muscular dystrophy. Quality of Life Research 28(suppl1): 109	- Publication type Conference abstract.
Quinn, Lori, Busse, Monica, Khalil, Hanan et al. (2010) Client and therapist views on exercise programmes for early-mid stage Parkinson's disease and Huntington's disease. Disability and rehabilitation 32(11): 917-28	- Phenomenon of interest Findings relate to barriers and facilitators to physical exercise, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Ramdharry, G.M.; Reilly, M.M.; Marsden, J.F. (2010) Exploring the experience of living with fatigue in people with Charcot-Marie-Tooth disease - A qualitative study. Neuromuscular Disorders 20(suppl1): 18-s19	- Publication type Conference abstract.
Rauch, A., Fekete, C., Cieza, A. et al. (2013) Participation in physical activity in persons with spinal cord injury: A comprehensive perspective and insights into gender differences. Disability and Health Journal 6(3): 165-176	- Country Study conducted in Switzerland.
Redfern, Clare and Coles, Alasdair (2015) Parkinson's Disease, Religion, and Spirituality. Movement disorders clinical practice 2(4): 341-346	- Study design Narrative review, not a systematic review.
Respondek, Gesine, Breslow, Diane, Amirghiasvand, Carol et al. (2023) The Lived Experiences of People with Progressive Supranuclear Palsy and Their Caregivers. Neurology and therapy 12(1): 229-247	- Country Mixed countries. Study conducted in UK, France, Italy, Belgium, Germany, Spain, the US and Japan. Results not presented separately for target country.
Sainsbury, S.A. and Lee, K. (2011) Art therapy in cases of acquired brain injury: Helping	- Publication type

Study	Reason for exclusion
participants find social context through creative self-expression. Brain Impairment 12(suppl1): 33	Poster abstract.
Salas, Christian E, Casassus, Martin, Rowlands, Leanne et al. (2018) "Relating through sameness": a qualitative study of friendship and social isolation in chronic traumatic brain injury. Neuropsychological rehabilitation 28(7): 1161-1178	- Phenomenon of interest Findings relate to reasons for social isolation after traumatic brain injury and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Shorland, J. and Douglas, J.M. (2010) Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. Brain Injury 24(4): 569-580	- Country Study conducted in Australia.
Skyrme, Sarah (2017) In and on their own terms: children and young people's accounts of life with Duchenne Muscular Dystrophy. Child Care in Practice 23(1): 77-89	- Phenomenon of interest Findings relate to the impact of Duchenne's on mobility, social stigma and sense of difference, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Soleimani, Mohammad Ali, Negarandeh, Reza, Bastani, Farideh et al. (2014) Disrupted social connectedness in people with Parkinson's disease. British journal of community nursing 19(3): 136-41	- Country Study conducted in Iran.
Soni-Jaiswal, A, Mercer, J, Jones, S A et al. (2016) Mucopolysaccharidosis I; Parental beliefs about the impact of disease on the quality of life of their children. Orphanet journal of rare diseases 11(1): 96	- Phenomenon of interest Findings relate to the impact of disorder on quality of life, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Soundy, Andrew and Condon, Nicola (2015) Patients experiences of maintaining mental well-being and hope within motor neuron disease: a thematic synthesis. Frontiers in psychology 6: 606	- Publication date Systematic review with 15/29 studies published 2010 or later, and 14/29 published pre-2010. Studies published 2010 onwards were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Soundy, Andrew; Stubbs, Brendon; Roskell, Carolyn (2014) The experience of Parkinson's disease: a systematic review and meta-ethnography. TheScientificWorldJournal 2014: 613592	- Publication date Systematic review with 16/37 studies published 2010 or later, and 21/37 studies published pre-2010. Studies published 2010 onwards were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Stennett, Andrea; De Souza, Lorraine; Norris, Meriel (2020) The meaning of exercise and physical activity in community dwelling people with multiple sclerosis. Disability and rehabilitation 42(3): 317-323	- Phenomenon of interest Findings relate to impact of, changes in, and importance of exercise and physical activity, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Stephens, Catherine; Neil, Rich; Smith, Paul (2012) The perceived benefits and barriers of sport in spinal cord injured individuals: a	- Phenomenon of interest Findings relate to barriers and facilitation to physical exercise, and not what works well or

Study	Reason for exclusion
qualitative study. Disability and rehabilitation 34(24): 2061-70	does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Sutton, Katie, Moore, Jaqualyn, Armes, Jo et al. (2023) Perceptions and experiences of the subjective well-being of people with glioblastoma: a longitudinal phenomenological study. Neuro-oncology practice 10(1): 79-88	- Phenomenon of interest Findings relate to experiences of glioblastoma, impact on daily life, and coping, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Swallow, V.; Smith, T.; Carolan, I. (2015) Promoting personal and family management of long-term conditions: Children and young people's views on desirable components for an interactive health communication application (IHCA). European Journal of Paediatric Neurology 19(suppl1): 93	- Publication type Conference abstract.
Tabuteau-Harrison, Sophie L; Haslam, Catherine; Mewse, Avril J (2016) Adjusting to living with multiple sclerosis: The role of social groups. Neuropsychological rehabilitation 26(1): 36-59	- Phenomenon of interest Findings relate to the advantages and disadvantages of social groups and social participation, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Tresman, R., Fraser, F., Brown, M. et al. (2016) Developing a model of reintegration into education post-medulloblastoma treatment in children: A thematic analysis. Neuro-Oncology 18(supplement3): iii145	- Publication type Conference abstract.
van Ierssel, Jacqueline, Pennock, Kaleigh Ferdinand, Sampson, Margaret et al. (2022) Which psychosocial factors are associated with return to sport following concussion? A systematic review. Journal of sport and health science 11(4): 438-449	- Study design Systematic review with 4/14 qualitative studies and 10/14 quantitative studies. Qualitative studies were checked against protocol – 1 was identified as potentially relevant and retrieved for further screening.
Vorster, Nitamarie, Evans, Kerry, Murphy, Nada et al. (2019) Powered standing wheelchairs promote independence, health and community involvement in adolescents with Duchenne muscular dystrophy. Neuromuscular disorders : NMD 29(3): 221-230	- Phenomenon of interest Findings relate to feedback on powered standing wheelchairs and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Waldboth, Veronika, Patch, Christine, Mahrer-Imhof, Romy et al. (2016) Living a normal life in an extraordinary way: A systematic review investigating experiences of families of young people's transition into adulthood when affected by a genetic and chronic childhood condition. International Journal of Nursing Studies 62: 44-59	- Population Systematic review including participants who are in protocol (7/33 participants with muscular dystrophies), and out of protocol (16/33 participants with cystic fibrosis, 10/33 participants with sickle cell diseases, and 2/33 participants with haemophilia). Studies including participants with muscular dystrophies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Wiblin, L. and Brittain, K. (2017) Connection in the context of atypical parkinsonism; a	- Publication type Conference abstract.

Study	Reason for exclusion
qualitative study. Age and Ageing 46(supplement2)	
Wiblin, Louise, Durcan, Rory, Lee, Mark et al. (2017) The Importance of Connection to Others in QoL in MSA and PSP. Parkinson's disease 2017: 5283259	- Phenomenon of interest Findings relate to the impact of social connection on quality of life, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Williams, Toni L; Smith, Brett; Papathomas, Anthony (2018) Physical activity promotion for people with spinal cord injury: physiotherapists' beliefs and actions. Disability and rehabilitation 40(1): 52-61	- Phenomenon of interest Findings relate to barriers to and facilitators for long-term physical activity, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Williams, Toni Louise; Smith, Brett; Papathomas, Anthony (2014) The barriers, benefits and facilitators of leisure time physical activity among people with spinal cord injury: a meta-synthesis of qualitative findings. Health psychology review 8(4): 404-25	- Country Systematic review with 3/18 of the included studies conducted in the UK, 6/18 in Canada, 6/18 in the US, 2/18 in Sweden, and 1/18 in the Netherlands. UK studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Willis, Claire, Nyquist, Astrid, Jahnsen, Reidun et al. (2018) Enabling physical activity participation for children and youth with disabilities following a goal-directed, family-centred intervention. Research in developmental disabilities 77: 30-39	- Country Study conducted in Norway.
Wilson, Eleanor and Aubeeluck, Aimee (2013) Residential care for those with neurological conditions: an exploration of three specialist neurological care facilities in the UK. Journal of Care Services Management 7(2): 61-71	- Phenomenon of interest Findings relate to feedback about residential neurological care facilities, and not what works well or does not work in accessing support for education, employment, and social participation for people with chronic neurological disorders.
Woolf, E.; Bennett, E.; Thomas, S. (2022) Acquired Brain Injury in Childhood: The Knowledge and Training Needs of Special Educational Needs Coordinators in UK Schools. Journal of Head Trauma Rehabilitation 37(6): e509	- Publication type Conference abstract.
Young, Kate; Bowers, Alison; Bradford, Natalie (2021) Families' experiences of child and adolescent brain tumor: A systematic review and synthesis of qualitative research. Psycho-oncology 30(10): 1643-1662	- Country Systematic review with 5/40 of the included studies conducted in the UK, 15/40 in the US, 8/40 in Canada, 3/40 in Australia, 3/40 in Belgium, 2/40 in Sweden, 1/40 in Hong Kong, 1/40 in Taiwan, 1/40 in Finland, and 1/40 in Australia, Singapore and New Zealand. UK studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.

Excluded economic studies

No economic searches were undertaken for this qualitative review.

Appendix K Research recommendations – full details

Research recommendations for review question: Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?

No research recommendations were made for this review question.