

**NATIONAL INSTITUTE FOR HEALTH AND CARE
EXCELLENCE**

NICE guidelines

DRAFT Equality and health inequalities assessment (EHIA)

**Rehabilitation for chronic neurological disorders including
acquired brain injury**

The considerations and potential impact on equality and health inequalities have been considered throughout the guidance development, maintenance and update process according to the principles of the NICE equality policy and those outlined in [Developing NICE guidelines: the manual](#).

STAGE 4. Development of guideline or topic area for update

(to be completed by the developer before consultation on the draft guideline or update)

Rehabilitation for chronic neurological disorders including acquired brain injury

Date of completion: March 2025

Focus of guideline or update: Chronic neurological disorders

4.1 From the evidence syntheses and the committee's considerations thereof, what were the main equality and health inequalities issues identified? Were any **further** potential issues identified (in addition to those identified during the scoping process) or any gaps in the evidence for any particular group?

Issues identified previously:

1. Geography: access to in-patient, out-patient and community rehabilitation
2. Lower socio-economic groups: impact on family life and income and/or lack of access to legal support or advice
3. Access to services: people with pre-existing physical and/or mental health and behavioural conditions, communication impairment, physical and learning disabilities, or frailty
4. Approaches to engagement with rehabilitation that are sensitive to cultural differences
5. Inequalities around poorer outcomes for looked after children
6. Age related service expectations: age related discrimination
7. Race and ethnicity: access to specialist rehabilitation services
8. Access to rehabilitation based on type of neurological condition
9. Delivery of interventions: remotely, via video or tele link (digital literacy)
10. Subgroups with particularly high rates of TBI: homeless people, prisoners, domestic violence victims, retired military personal, retired sportsmen and women.
11. Children and young people

One further potential issue identified (in addition to those identified during the scoping process) was:

12. Population with complex needs (social care)

4.2 How have the committee's considerations of equality and health inequalities issues identified in 2.2, 3.2 and 4.1 been reflected in the guideline or update and any draft recommendations?

1. Geography: access to in-patient, out-patient and community rehabilitation

Rehabilitation services are organised differently in different parts of the country and therefore access to services varies. Rehabilitation services or facilities can be centralised in specific locations requiring people to travel long distances to access specialised care. Public transportation options may be limited or not accessible for individuals with mobility issues, further complicating access. The committee discussed that integrative services could facilitate a holistic approach that increases access to different services, whilst putting the needs and experience of people at the centre of how services are organised and delivered. Access to community activities and groups depends on the availability of these services and the committee were aware that many groups and activities are delivered at least partially online, especially since COVID-19. Therefore, they recommended considering these online options, whilst also considering struggles with access to IT equipment (see digital literacy section), for people facing geographical barriers to accessing suitable communities.

1.1.3 Design rehabilitation services for people with a chronic neurological disorder that:

- address their rehabilitation needs, from when they first develop symptoms or impairments, or they are diagnosed*
- have lifelong support and care in mind*
- operate across all health and care settings, including hospital and community rehabilitation services, primary care and home care (including third sector and private sector providers)*
- take into account the mix of specialist neurorehabilitation services and general rehabilitation services required.*

1.1.4 Establish integrated, collaborative and flexible clinical pathways across hospital and community rehabilitation services to address people's needs throughout their life.

1.3.6 If availability of specialist neurorehabilitation services is restricted in some areas or for some people (including for people living in rural areas or with rare conditions) collaborate within and between integrated care systems to:

- enable access to specialist care where possible*
- share specialist advice and expertise with non-specialist services*
- explore provision of general community rehabilitation services supported by specialist services.*

1.4.1 Service providers should communicate and collaborate, including across specialities, and with the third sector and private sector, to ensure care pathways are responsive to people's needs, including when people are moving between services.

1.8.8 Ask the person about:

- environmental and wider social factors that might encourage or prevent them from taking part in rehabilitation (for example, access to community resources and, equipment for rehabilitation and housing)*

1.16.5 Discuss any barriers preventing the person from achieving their physical activity goals and work together to overcome these. Barriers could relate to:

- availability of suitable facilities to undertake physical activity.*

1.25.7 Consider online options for social activities if in-person activities are scarce, for example, in rural areas, or travel is challenging.

2. Lower socio-economic groups: impact on family life and income and/or lack of access to legal support or advice

The committee acknowledged that people from lower socioeconomic groups could be particularly affected by barriers when accessing health and social care. Many people with chronic neurological disorders require more help than just signposting and information giving. The committee discussed the importance of having a single point of contact, to manage and coordinate rehabilitation care, provide support and information, and facilitate access to services such as social care or referral to specialists. The contact would be agreed upon by the care team and could be a key worker or a complex case manager and community or hospital-based. Those with complex needs may require more intensive support with a complex case manager, to integrate health and social care. The committee discussed that many people receive a complex case manager from private health providers because of an insurance claim for an accident. While complex case management can be costly, it may reduce unplanned care and improve efficiency, potentially relieving pressure on NHS resources. The committee highlighted benefits beyond cost analysis, including reduced inappropriate care settings and improved access to housing and welfare.

The committee also discussed that chronic neurological conditions often require ongoing treatments, therapies, and medications, which can be costly. People from lower socioeconomic backgrounds may struggle to afford these services, including specialist consultations, rehabilitation therapies, assistive devices, and long-term care needs. The financial burden can lead to delayed or reduced access to essential services.

1.2.1 Commission services to ensure that people with a chronic neurological disorder have access to a key contact, key worker or a complex case manager depending on their rehabilitation needs.

1.3.5 Ensure that healthcare and social care practitioners know how to commission high-cost specialist equipment and services.

1.11.1 As part of the person's rehabilitation plan, assign them a single point of contact to:

- help them understand and navigate rehabilitation services*
- coordinate their rehabilitation plan*
- support them in accessing rehabilitation services, if needed*
- refer them for other services, if needed*

1.11.5 Consider assigning a key worker if the person has:

- impaired cognitive or executive function that impacts on their ability to self-manage their condition or navigate rehabilitation services*
- an unpredictable or rapidly changing neurological condition*

- *multiple rehabilitation needs that require rehabilitation across multiple services and areas of care*
- *the potential to develop new needs around accessing care and there are associated family support needs, (for example in the case of a child or young person moving between education settings).*

1.11.6 Consider assigning a complex case manager if the person has severe, complex and long-term rehabilitation needs and:

- *impaired cognitive or executive function that severely impacts their ability to self-manage their condition or navigate rehabilitation services and/or*
- *is unable to advocate for themselves and has no-one to advocate for them (some people may have a legal right to advocacy) and/or*
- *has serious comorbidities (for example, poorly controlled diabetes or epilepsy), a learning disability, misuses drugs or alcohol or has neurobehavioral symptoms that place them at risk of harm to themselves or others.*

1.13.2 Explain what financial support is available to assist with rehabilitation in relation to activities of daily living, travel, and social and leisure activities, for example, travel support, provision of wheelchairs and personal assistance via personal budgets and direct payments.

1.22.8 Give the person advice and support to access, or to access funding for equipment, assistive technology or environmental adaptations in their home or residential setting, education or workplace setting where this is not available from the NHS. This may include funding or provision from the government, their local authority or the voluntary sector.

3. Access to services: people with pre-existing physical and/or mental health and behavioural conditions, communication impairment, physical and learning disabilities, or frailty

The committee considered that for people with pre-existing health or behavioural conditions, accessing healthcare and social care becomes more complex due to the interplay of multiple factors. These individuals may face greater challenges in navigating systems, receiving timely and appropriate treatment, and managing their conditions. Therefore, services should aim to provide clear and simple information, and provide appropriate support when required.

1.7.2 Make a brief assessment of the person's social, psychological, emotional, cognitive and communication needs, as well as their physical health and level of impairment, to help decide whether a holistic assessment is needed.

1.8.9 In addition to their neurological condition or injury, think about how other health conditions, including mental health conditions, may affect their rehabilitation.

1.8.10 Encourage the person to talk freely about how their life has been impacted by their neurological condition.

1.10.2 When agreeing the interventions and approaches that will constitute the rehabilitation plan, think about and include in the plan:

- *modifying interventions in line with factors such as developmental age and cognitive abilities.*

1.15.5 Check for treatable factors that may be affecting fatigue, for example, mood difficulties, sleep problems, nutritional problems, abnormal endocrine function, medication and some neurological symptoms, including vestibular symptoms. Refer for treatment, as necessary.

1.18.13 If the person has difficulty engaging in talking therapies because of cognitive or communication problems, or where speaking is not the person's preferred way of communicating, consider creative therapies.

1.18.16 Treat diagnosed post-traumatic stress disorder, anxiety and depression in adults with chronic neurological disorders, and depression in children and young people with chronic neurological disorders as part of their rehabilitation, and based on NICE's guidelines on:

- *post-traumatic stress disorder*
- *social anxiety disorder*
- *generalised anxiety disorder and panic disorder in adults*
- *depression in adults*
- *depression in adults with a chronic physical health problem*

1.19.5 When deciding which assessment techniques to use and how to interpret any results, take into account the following:

- *the person's cognitive ability before neurological injury or development of their neurological disorder*
- *the demands of the tests and functional assessments and the environment in which they are being undertaken*
- *how symptoms such as fatigue, low mood or pain may affect testing and assessment*
- *the impact of any other health conditions on testing and assessment.*

4. Approaches to engagement with rehabilitation that are sensitive to cultural differences

The committee discussed that cultural attitudes may influence whether individuals seek help. Stigma or discrimination around neurological disabilities can lead to feelings of shame or reluctance to engage with rehabilitation services. Language barriers and lack of culturally competent care may also deter people from accessing services. Therefore, the committee agreed that service assessments and services should consider and be mindful of people's cultural differences.

1.8.8 Ask the person about:

- *their background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and interests*

1.16.5 Discuss any barriers preventing the person from achieving their physical activity goals and work together to overcome these. Barriers could relate to:

- *the need for support, which may be practical, physical or cognitive*
- *cultural or socioeconomic factors*
- *availability of suitable facilities to undertake physical activity.*

1.27.6 When discussing, assessing and providing interventions connected with intimate or sexual relationships and sex, take into account the person's gender identify, sexual orientation, and any religious and cultural beliefs.

5. Inequalities around poorer outcomes for looked after children

The guideline did not explicitly look for evidence about interventions that would help improve poorer outcomes for looked after children, however, having a single point of contact (details in lower socio-economic groups section) to including key workers and complex case managers will help those with complex needs such as looked after children navigate the system. This will also be true for adults who were previously looked after children. Looked after children are more likely to have special educational needs. A special needs coordinator is also included in the definition of a single point of access.

1.6.2 If rehabilitation has begun or elements of a rehabilitation needs assessment have been carried out before hospital discharge, the inpatient multidisciplinary team, and community and primary care practitioners should jointly agree who will be the contact for rehabilitation. This person may be a clinical nurse specialist, GP, rehabilitation physician, special educational needs coordinator, allied health professional, family support worker, social worker, case manager, disability paediatrician or speciality-specific coordinator, for example, a neuro navigator.

1.8.21 For children and young people with severe complex needs, assess their rehabilitation needs as part of an education, health and care plan (EHCP), which should cover special educational needs, social care and healthcare, including rehabilitation. For more information, see [NICE's guideline on disabled children and young people up to 25 with severe complex needs](#).

1.18.7 Make referrals to emotional health and mental wellbeing services with the most appropriate expertise, based on the person's needs and circumstances.

Assessments or interventions may be provided by:

- *neurorehabilitation services*
- *mental health services*
- *third sector providers (for example, Headway or other charities, community groups and social enterprises)*
- *education services (for children and young people, those delivered by a special educational needs coordinator or through an emotional literacy support assistant programme, for example).*

6. Age related service expectations: age related discrimination

The committee developed recommendations to design inclusive services that reduced discrimination. They referenced other guidelines about home care and preventing falls for older people who also have a chronic neurological disorder in the guideline section about independent living, equipment and environmental adaptations. The committee noted that some people are excluded from receiving rehabilitation services (such as, due of the age and frailty of the person, or because the clinician does not think they will benefit from these therapies or treatments). The committee discussed that tailored solutions are

needed to address these specific challenges and ensure equitable care for individual, and therefore holistic assessments should be conducted to understand the person's needs and requirements in the context if any age related issues also, amongst others.

7. Race and ethnicity: access to specialist rehabilitation services

The committee focused many of the recommendations on how specialist and non-specialist rehabilitation services needed to work more closely together to deliver more effective and efficient services across the different treatment and intervention domains and how non-specialist rehabilitation services needed to adapt to meet the needs of the many people with chronic neurological disorders in the community. They agreed it was important for specialist and generalists' services to work together to build more expert capacity within the local area workforce. The guideline did not therefore explicitly look for evidence about interventions that would help increase access to specialist services for particular groups.

1.3.2 Ensure there are separate local service level agreements in place for the provision of mental health services for adults, and for children and young people, with a chronic neurological disorder.

1.3.3 Build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation.

1.3.4 Ensure that GPs and other primary care practitioners know how to recognise emerging rehabilitation needs because of an existing chronic neurological disorder, and know when and how to refer people to rehabilitation specialists. For example, using expertise from specialist neurorehabilitation services and maintaining up-to-date information on options for local rehabilitation services.

1.3.6 If availability of specialist neurorehabilitation services is restricted in some areas or for some people (including for people living in rural areas or with rare conditions) collaborate within and between integrated care systems to:

- enable access to specialist care where possible*
- share specialist advice and expertise with non-specialist services*
- explore provision of general community rehabilitation services supported by specialist services.*

8. Access to rehabilitation based on type of neurological condition

The committee discussed ensuring equitable access to high-quality neurorehabilitation care, even when specialist services are limited or geographically inaccessible. By collaborating within and between integrated care systems, areas with fewer resources can still benefit from expert guidance, ensuring patients receive appropriate care.

The committee discussed how each person has their unique set of neurological impairments or disabling neurological symptoms that accompany them, in the context of their unique life. The committee agreed that this presents unique access challenges due to the varying nature of the condition and the specific care needs involved. The committee noted that some people are excluded from receiving rehabilitation services (such as, due to the age and frailty of the person, the progressive nature of their condition, or because the clinician does not think they will benefit from this care).

The committee discussed that tailored solutions are needed to address these specific challenges and ensure equitable care for individual, and therefore holistic assessments should be conducted to understand the person's needs and requirements. The committee felt strongly about recommending against this discriminatory approach. There is also discrimination against some conditions which are harder to diagnose than others. The committee recommended in 1.5.1 and 1.7.1 that rehabilitation can start being considered before a diagnosis is made. It can be based on symptoms and impairment alone, for example, functional neurological disorder (FND) often takes a long time to receive a diagnosis which has previously restricted access to treatment for people with clear rehabilitation needs based on a suspected FND diagnosis. Therefore, these recommendations offer potential for a more equitable service for people with FND.

1.3.6 If availability of specialist neurorehabilitation services is restricted in some areas or for some people (including for people living in rural areas or with rare conditions) collaborate within and between integrated care systems to:

- enable access to specialist care where possible*
- share specialist advice and expertise with non-specialist services*
- explore provision of general community rehabilitation services supported by specialist services.*

1.5.1 Ensure that the need for rehabilitation is identified as early as possible in people with a suspected or confirmed chronic neurological disorder.

1.7.1 Think about undertaking, or making a referral for, a holistic rehabilitation needs assessment:

- as soon as a diagnosis is established or*
- based on symptoms or impairment (even if a chronic - neurological disorder is suspected but not yet confirmed).*

1.8.17 Do not exclude someone from any aspect of a holistic needs assessment based on their memory or learning difficulties.

1.8.18 Make reasonable adjustments and adaptations to enable a person with memory or learning difficulties to engage in rehabilitation.

1.10.3 Focus on interventions for optimising or maintaining the person's functioning and abilities, even when they have a time-limited prognosis or the potential for improvement appears to be limited.

1.11.5 Consider assigning a key worker if the person has:

- impaired cognitive or executive function that impacts on their ability to self-manage their condition or navigate rehabilitation services*
- an unpredictable or rapidly-changing neurological condition*
- multiple rehabilitation needs that require rehabilitation across multiple services and areas of care*
- the potential to develop new needs around accessing care and there are associated family support needs (for example, in the case of a child or young person moving between education settings).*

1.11.6 Consider assigning a complex case manager if the person has severe, complex and long-term rehabilitation needs and:

- impaired cognitive or executive function that severely impacts their ability to self-manage their condition or navigate rehabilitation services and/or
- is unable to advocate for themselves and has no-one to advocate for them (some people may have a legal right to advocacy) and/or
- has serious comorbidities (for example, poorly controlled diabetes or epilepsy), a learning disability, misuses drugs or alcohol or has neurobehavioral symptoms that place them at risk of harm to themselves or others.

9. Delivery of interventions: remotely, via video or tele link (digital literacy)

Digital literacy challenges are compounded by cognitive, physical, and socio-economic barriers. These difficulties can hinder the ability for people to fully benefit from digital resources in education, healthcare, and social interactions. Addressing these challenges requires tailored digital tools, improved access to technology, and support for both people and their families to enhance their digital literacy and ensure equitable access to essential services.

1.10.4 Deliver rehabilitation interventions in settings that are appropriate to the person's rehabilitation goals and meet their preferences. This may be at home, school, work or community settings, or remotely, where appropriate.

1.12.5 Ensure people have access to the right equipment, technology and advice before rehabilitation ends, to help them prepare for changes that may happen in the future.

1.17.3 Think about using gaming modalities or virtual reality to help engagement in training and exercises to improve stability, mobility or limb function.

1.19.10 Discuss ways to help the person to compensate for, and manage, difficulties with memory and learning in daily life. For example, cueing and prompting by others, changes to the person's environment and use of compensatory aids such as smart phone apps, paper diaries, electronic calendars, video games, virtual reality and other computer-based exercises.

1.3.7 Consider funding local social and leisure group activities to support rehabilitation in the community. When doing this take account of the following:

- people do not always want to socialise with people who have the same condition as them
- some people may want to socialise with others facing similar challenges
- younger people may feel more comfortable socialising with their peers
- people with a functional neurological disorder may not find a group approach helpful
- some people may feel more comfortable in social and leisure groups for the wider community if they are reassured these groups will be accessible to them.

1.8.8 Ask the person about:

- their background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and interests

- *their activities of daily living (including self-care skills, domestic and leisure activities, and productivity) and how this has changed or is changing*
- *developmental milestones and play in the case of children*
- *what would motivate them to engage in rehabilitation and what is most important in their life*
- *environmental and wider social factors that might encourage or prevent them from taking part in rehabilitation (for example, access to community resources and equipment for rehabilitation and housing).*

1.13.1 Give personalised information to people with a chronic neurological disorder, and their family or carers, if appropriate, about:

- *their condition and rehabilitation needs, including any anticipated future needs*
- *how to access rehabilitation services and social care*
- *how to get advice about work and education, housing, benefits and legal support*
- *voluntary and community organisations, local support groups, national charities and other third sector organisations that can provide further information and support.*

1.13.2 Explain what financial support is available to assist with rehabilitation in relation to activities of daily living, travel, and social and leisure activities, for example, travel support, provision of wheelchairs and personal assistance via personal budgets and direct payments.

1.13.3 Advise people (and advocate for them as necessary) that their local authority has a statutory requirement, under the Care Act 2014 and Children and Families Act 2014, to assess their care and support needs, when requested.

1.13.4 Continue to offer personalised information and advice as and when the person's rehabilitation needs or circumstances change, for example, at discharge from hospital or rehabilitation services, at different life stages or as their condition progresses.

1.13.5 Consider joined-up education and training interventions for the person, and their family or carers, if appropriate, to deliver different elements of their rehabilitation plan at the same time, for example, training in cognitive strategies alongside use of equipment for independent living, both of which might happen in the person's home.

1.13.6 Help the person decide what and how to communicate to others about their condition and rehabilitation needs. Think about:

- *the use of a disability passport*
- *information to share with community staff (especially when adjustments to services are required)*
- *information to share socially with others.*

1.25.1 Talk to the person about any barriers preventing them from achieving their social participation goals and work together to overcome these barriers.

10. Subgroups with particularly high rates of TBI: homeless people, prisoners, domestic violence victims, retired military personal, retired sportsmen and women

The committee discussed that subgroups with high rates of traumatic brain injury often have multiple needs, are unable to advocate for themselves and therefore may have more difficulty accessing systems. These subgroups may meet the criteria for a complex case manager. The committee agreed that personalised support helps identify employment barriers and that people often lack awareness of work options. They recommended providing accessible information on employment, housing, benefits, and legal support. They also noted issues with access to equipment, home adaptations, and transport, especially for those with cognitive symptoms. The committee emphasised the importance of proactive, clear information during service transitions and for family support, while acknowledging the need for tailored education to improve access to services. They also discussed the challenge of disclosing condition-related needs and the importance of reducing barriers and building confidence.

People with chronic neurological disorders can be socially isolated, making it more difficult for them to access support networks. Those with chronic conditions may struggle to maintain relationships, resulting in fewer social resources to assist with transportation, advocacy, or emotional support during treatments.

1.3.7 Consider funding local social and leisure group activities to support rehabilitation in the community. When doing this take account of the following:

- people do not always want to socialise with people who have the same condition as them*
- some people may want to socialise with others facing similar challenges*
- younger people may feel more comfortable socialising with their peers*
- people with a functional neurological disorder may not find a group approach helpful*
- some people may feel more comfortable in social and leisure groups for the wider community if they are reassured these groups will be accessible to them.*

1.8.8 Ask the person about:

- their background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and interests*
- their activities of daily living (including self-care skills, domestic and leisure activities, and productivity) and how this has changed or is changing*
- developmental milestones and play in the case of children*
- what would motivate them to engage in rehabilitation and what is most important in their life*
- environmental and wider social factors that might encourage or prevent them from taking part in rehabilitation (for example, access to community resources and equipment for rehabilitation and housing).*

1.11.6 Consider assigning a complex case manager if the person has severe, complex and long-term rehabilitation needs and:

- impaired cognitive or executive function that severely impacts their ability to self-manage their condition or navigate rehabilitation services and/or*
- is unable to advocate for themselves and has no-one to advocate for them (some people may have a legal right to advocacy) and/or*
- has serious comorbidities (for example, poorly controlled diabetes or epilepsy), a learning disability, misuses drugs or alcohol or has neurobehavioral symptoms that place them at risk of harm to themselves or others.*

1.13.1 Give personalised information to people with a chronic neurological disorder, and their family or carers, if appropriate, about:

- their condition and rehabilitation needs, including any anticipated future needs*
- how to access rehabilitation services and social care*
- how to get advice about work and education, housing, benefits and legal support*
- voluntary and community organisations, local support groups, national charities and other third sector organisations that can provide further information and support.*

1.13.2 Explain what financial support is available to assist with rehabilitation in relation to activities of daily living, travel, and social and leisure activities, for example, travel support, provision of wheelchairs and personal assistance via personal budgets and direct payments.

1.13.3 Advise people (and advocate for them as necessary) that their local authority has a statutory requirement, under the Care Act 2014 and Children and Families Act 2014, to assess their care and support needs, when requested.

1.13.4 Continue to offer personalised information and advice as and when the person's rehabilitation needs or circumstances change, for example, at discharge from hospital or rehabilitation services, at different life stages or as their condition progresses.

1.13.5 Consider joined-up education and training interventions for the person, and their family or carers, if appropriate, to deliver different elements of their rehabilitation plan at the same time, for example, training in cognitive strategies alongside use of equipment for independent living, both of which might happen in the person's home.

1.13.6 Help the person decide what and how to communicate to others about their condition and rehabilitation needs. Think about:

- the use of a disability passport*
- information to share with community staff (especially when adjustments to services are required)*
- information to share socially with others.*

1.22.7 Identify and address any environmental barriers to activities of daily living in the home or residential setting (for example moving furniture or commonly used cooking or bathing items to a more accessible place) and assess the need for moving and handling equipment (for example a bed hoist) and environmental adaptations.

1.25.1 Talk to the person about any barriers preventing them from achieving their social participation goals and work together to overcome these barriers.

11. Children and young people

The committee discussed that for adults, while there are good services and pathways for severe neurological problems, there are significant gaps for moderate and mild conditions. Also, generally, there are no well-established pathways beyond inpatient

services, and the situation is worse for children and young people. The committee were aware that rehabilitation needs and preferences of children and young people will change as they grow and develop. Therefore, follow-ups and reviews should be planned around these milestones to capture any amendments to a child or young person's rehabilitation needs and goals. Professionals will also need to continue adapting support, information and complexity of rehabilitation discussions in line with a child's chronological and neurodevelopmental age. The committee discussed the current challenges of commissioning care for people with chronic neurological disorders, especially during transitions from child to adult services. These challenges arise from differences in service organisation and funding, and variations in specialist service availability across the country. They discussed that addressing these challenges and ensuring clear commissioning responsibility may require establishing consistent eligibility criteria and adopting joint commissioning approaches. It may also require reallocating existing resources and funds between services to meet the needs of individuals transitioning from children and young people to adult services. The committee signposted to the NICE guideline on Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education [NG213].

1.1.5 Agree who has overall designated responsibility for implementing clinical pathways for children, and, separately, for adults, taking into account local and national commissioning responsibilities.

1.2.2 Produce service specifications for integrated rehabilitation care for people with a chronic neurological disorder to include the following:

- play therapies that facilitate the delivery of rehabilitation interventions for children*

1.3.1 Ensure collaboration between commissioning bodies from healthcare and social care and other relevant community service providers, for example education services for children.

1.3.2 Ensure there are separate local service level agreements in place for the provision of mental health services for adults, and children and young people, with a chronic neurological disorder.

1.8.8 Ask the person about:

- developmental milestones and play in the case of children.*

1.18.16 Treat diagnosed post-traumatic stress disorder, anxiety and depression in adults with chronic neurological disorders, and depression in children and young people with chronic neurological disorders as part of their rehabilitation, and based on NICE's guidelines on:

- depression in children and young people.*

1.8.21 For children and young people with severe complex needs, assess their rehabilitation needs as part of an education, health and care plan (EHCP), which should cover special educational needs, social care and healthcare, including rehabilitation. For more information, see NICE's guideline on disabled children and young people up to 25 with severe complex needs.

1.9.3 Use age-specific approaches to engage children and young people in goal setting conversations.

1.9.4 Agree goals based on the person's wishes and aspirations that:

- take account of developmental challenges, in the case of children and young people.*

1.9.8 Frequently adjust rehabilitation goals and plans for children and young people in response to their growth and developmental stage.

1.9.10 Use this information, together with the person's likely developmental trajectory in the case of children and young people, when setting education and work goals with them.

1.10.2 When agreeing the interventions and approaches that will constitute the rehabilitation plan, think about and include in the plan:

- modifying interventions in line with factors such as developmental age and cognitive abilities.*

1.11.5 Consider assigning a key worker if the person has:

- the potential to develop new needs around accessing care and there are associated family support needs (for example, in the case of a child or young person moving between education settings)*

1.12.4 Plan follow-up for children at key neurodevelopmental stages, recognising that rehabilitation needs and goals may change over time and that new symptoms may emerge.

1.17.1 If the person has problems with stability, mobility, or upper or lower limb function, work with them to develop specific and targeted training and exercises. This may include:

- exercise and training delivered through play therapy (for children).*

1.18.7 Make referrals to emotional health and mental wellbeing services with the most appropriate expertise, based on the person's needs and circumstances.

Assessments or interventions may be provided by:

- education services (for children and young people, those delivered by a special educational needs coordinator or emotional literacy support assistant programme, for example).*

1.23.1 As soon as possible after suspecting or diagnosing a chronic neurological disorder in a child or young person, inform their school or college.

1.23.2 Provide the school or college with information about the child's or young person's condition and its prognosis, and their rehabilitation needs.

1.23.3 Discuss and agree the support, equipment, adaptations (including environmental adaptations) or adjustments needed to facilitate the child's or young person's rehabilitation and participation in education.

1.23.4 Ensure there is:

- *a named healthcare practitioner that education practitioners can contact if they are concerned about the rehabilitation needs of the child or young person*
- *two-way communication and information sharing between rehabilitation and education practitioners, including during periods of transition, for example, when the child or young person moves to a different school or college, or their teachers change.*

1.23.5 Discuss at regular intervals whether the school or college remains right for the child or young person or whether a different education setting is needed

1.23.6 Regularly review education, health and care plans where these include rehabilitation provision, especially if the person has a chronic neurological condition that is progressive or fluctuating.

One further potential issue identified (in addition to those identified during the scoping process) was:

1. Population with complex needs (social care)

Access to social care services for people with complex needs, particularly those with neurological conditions, is often more complicated due to the diverse and ongoing requirements that these individuals have. Complex needs may include a combination of physical, cognitive, emotional, behavioural, and social challenges that require integrated and individualised care plans. The access requirements for this group of people typically involve overcoming various barriers related to healthcare, social services, and support systems. The committee referred to NICE guidance on social work with adults experiencing complex needs [NG216] and the Care Act 2014 for further support and the NICE guideline on Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education [NG213].

1.8.20 Discuss with the person, and their family or carers, if appropriate, whether they have social care needs and whether a social care needs assessment is required. For more information, see NICE's guideline on social work with adults experiencing complex needs.

1.11.2 Assess the person's ability, or that of their family or carers, if appropriate, to self-manage their rehabilitation and agree the most appropriate type of single point of contact for their rehabilitation. This may be a key contact, key worker or complex case manager.

1.11.5 Consider assigning a key worker if the person has:

- *impaired cognitive or executive function that impacts on their ability to self-manage their condition or navigate rehabilitation services*
- *an unpredictable or rapidly changing neurological condition*
- *multiple rehabilitation needs that require rehabilitation across multiple services and areas of care*
- *the potential to develop new needs around accessing care and there are associated family support needs, (for example in the case of a child or young person moving between education settings).*

1.12.1 Update the person about their single point of contact (key contact, key worker or complex case manager) if this is going to change after rehabilitation has ended and make sure they know how to get in touch if their symptoms or level of impairment changes.

1.13.1 Give personalised information to people with chronic neurological disorders, and their families and carers, if appropriate, about:

- their condition and rehabilitation needs, including any anticipated future needs*
- how to access rehabilitation services and social care*
- how to get advice about work and education, housing, benefits and legal support*
- voluntary and community organisations, local support groups and national charities and other third sector organisations that can provide further information and support.*

1.13.3 Advise people (and advocate for them as necessary) that their local authority has a statutory requirement, under the Care Act 2014 and Children and Families Act 2014, to assess their care and support needs, when requested.

1.13.6 Help the person decide what and how to communicate to others about their condition and rehabilitation needs. Think about:

- the use of a disability passport*
- information to share with community staff (especially when adjustments to services are required)*
- information to share socially with others.*

4.3 Could any draft recommendations potentially increase inequalities?

It is unlikely that any draft recommendations would increase inequalities.

4.4 How has the committee's considerations of equality and health inequalities issues identified in 2.2, 3.2 and 4.1 been reflected in the development of any research recommendations?

Personal care and activities of daily living in people with a chronic neurological disorder

The healthcare system faces a significant burden due to the unmet needs of children and adults with chronic neurological conditions. The evidence review for this question highlighted several groups with no trial data on strategies to improve or maintain independence in daily activities: children and young people with chronic neurological disorders, adults with acquired spinal cord injuries, adults with acquired peripheral nerve disorders, and adults with functional neurological disorders. There is limited research showing the effectiveness of targeted, specialized interventions aimed at promoting independence in daily activities for individuals with chronic neurological conditions across their entire life span.

Stability, mobility and upper limb function in people with a chronic neurological disorder

By identifying effective and cost-efficient interventions to improve or maintain stability, mobility, and upper limb function, rehabilitation therapists can choose and implement the most suitable treatments for their patients. This will enhance the effectiveness and efficiency of rehabilitation, potentially improving outcomes and reducing the length of stay or rehabilitation duration. This evidence review found that several populations lacked trial data on interventions for improving or sustaining stability, mobility, and upper limb function, including children and young people with acquired brain injuries, acquired spinal cord injuries, acquired peripheral nerve disorders, and functional neurological disorders. Chronic neurological disorders can severely affect daily functioning and lead to disability. Effective interventions to improve these functions can help children and young people regain independence, lessen symptom impact, and enhance social, educational, and personal functioning.

Rehabilitation for cognitive function in people with chronic neurological diseases

There are no relevant equality considerations.

Emotional health and mental wellbeing in children and young people with a chronic neurological disorder

There was limited evidence for the effectiveness and cost effectiveness of psychological provision with or without other interventions (physical/social) for children and young people with a chronic neurological disorder for improving and sustaining emotional health and mental wellbeing. This area was considered important to research so that the emotional wellbeing of children and young people can be supported throughout their rehabilitation journey with the right psychological tools to aid their rehabilitation and potentially reduce the development of chronic and complex issues which may require specialist level support by improving patient outcomes earlier in the pathway. In addition, this research recommendation would capture looked after children and children and access to services for young people with pre-existing physical and/or mental health and behavioural conditions, communication impairment, physical and learning disabilities. Research allows for a deeper understanding of which interventions work best for different types of CNS and patient profiles. This leads to more personalized treatment plans that address the unique emotional and psychological challenges each patient faces. Research also ensures that interventions are adapted to the cultural, social, and personal contexts of patients, making treatments more relevant and effective for a diverse range of individuals.

Emotional health and mental wellbeing in adults with a functional neurological disorder

There was limited evidence for the effectiveness and cost effectiveness of psychological provision with or without other interventions (physical/social) for adults with a functional neurological disorder (FND) for improving and sustaining emotional health and mental wellbeing. This research recommendation relates to the equalities and health inequalities (EHI) group of access to rehabilitation based on type of neurological condition. This area was considered important to research as effective interventions for FND could enhance emotional health and help patients regain autonomy in everyday tasks, reduce the impact of their symptoms, and improve social, occupational, and personal functioning. This question therefore also helps address the EHI area of access requirements based on subgroups with social barriers. FND is often associated with co-occurring mental health conditions such as anxiety, depression, and trauma-related disorders and researching effective interventions can help address these emotional difficulties, providing patients with the psychological tools to cope with co-occurring mental and/or any pre-existing disorders. This question therefore also considers the EHI group of access to services for pre-existing physical and/or mental health and behavioural conditions, communication impairment, physical and learning disabilities.

4.5 Based on the equality and health inequalities issues identified in 2.2, 3.2 and 4.1, do you have representation from relevant stakeholder groups for the guideline or update consultation process, including groups who are known to be affected by these issues? If not, what plans are in place to ensure relevant stakeholders are represented and included?

We have appropriate representation on our list of registered stakeholders from groups that can help explore equality and health inequalities issues. This includes organisations working with a range of neurological disorder groups with complex needs, providing personalised services and support; organisations representing a range of neurological conditions, disabilities and health conditions, for both adults and children and young people; various local councils, public health organisations, and NHS trusts that likely address socioeconomic factors; organisations representing a variety of carers, health, mental health and social care professionals involved in rehabilitation care, including case manager associations; occupational health based organisations; organisations representing black and minority ethnic people; organisations representing consumer voices and those in subgroups with complex needs such as people in prisons.

We also have engagement from a wide range of national health organisations, local authorities, networks, NHS trusts (including children and young people focused), and specialised health groups that can provide insights into various aspects of health inequalities.

Note: To be updated after further discussion with the Public Involvement Programme team.

4.6 What questions will you ask at the stakeholder consultation about the impact of the guideline or update on equality and health inequalities?
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To be updated following discussions with QA team and wider project team

Completed by developer: Lisa Boardman

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Approved by committee chair: Ian A Bernstein

Date: 10/03/2025

Approved by NICE quality assurance lead: Sharon Swain

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