

The Royal College of Speech and Language Therapists Northern Ireland (RCSLT NI) Response to the Regional Review of Neurology Services

August 2025

Introduction

The Royal College of Speech and Language Therapists (RCSLT NI) welcomes the publication of the *Regional Review of Neurology Services* and supports its focus on improving person-centred, equitable, and effective care for people living with neurological conditions. We particularly endorse the report's emphasis on workforce capacity, addressing service gaps, and optimising resources.

However, the report does not adequately reflect the critical role of Speech and Language Therapy (SLT) in neurology services. Communication and swallowing difficulties which are life-changing and often life-threatening are not referenced. This omission risks underestimating the importance of SLT in delivering the holistic, multidisciplinary care required by people with neurological conditions. We were disappointed that communication and swallowing difficulties were not included within any of the definitions, despite the high prevalence and life changing impact of the difficulties.

Below, we outline the main impacts of speech, language and communication needs (SLCN) and swallowing difficulties (dysphagia) in people living with a neurological disorder. We also note our key points and recommendations, aligned with the four priority areas identified in the Review. The information included in this response has been collated with input from specialist speech and language therapists working across Northern Ireland with patients with a range of neurological conditions.

The RCSLT NI welcome any opportunity to engage with the Department of Health to ensure that the review and subsequent implementation plans include the needs of those in Northern Ireland living with SLCN and/ or swallowing needs.

For further information or queries please contact Ruth Sedgewick, Head of RCSLT NI.

Ruth.sedgewick@rcslt.org

Thank you.

Impact of Speech, Language, Communication, Eating, Drinking and Swallowing Changes in Progressive and Acquired Neurological Conditions

SLCN and dysphagia are common and often severe in people with neurological conditions, yet they are frequently under-recognised within service planning. The RCSLT strongly advocate for the explicit inclusion of both SLCN and dysphagia in all strategic developments, service standards, and care models for neurology.

Key Statistics -

Motor Neurone Disease (MND):

- SLCN: Around 80-95% of people with MND are unable to meet their daily communication needs without the support of Alternative Augmentative Communication systems (Beukleman et al, 2011).
- Dysphagia: Up to 80% of people with MND will experience dysphagia influencing the prognosis of the disease (Romero-Gangonells et al, 2020).

Parkinson's Disease:

- SLCN: Around 90% of individuals experience speech and communication difficulties (Johansson et al, 2019).
- Dysphagia: More than 80% experience swallowing problems at some stage (Suttrup & Warnecke, 2016).

Multiple Sclerosis (MS):

- SLCN: Around 40% experience changes in communication (Barrera, 2012)
- Dysphagia: 45% experience swallowing difficulties (Mirmosayyeb et al, 2023).

Huntington's Disease (HD):

- SLCN: 93% experience some form of communication impairment (Rusz et al, 2014).
- Dysphagia: Dysphagia increases as the disease progresses affecting 35% of patients in the early stages, 94% in moderate stages and 100% in the advanced stages (Raines et al, 2025).

Functional Neurological Disorder (FND):

- SLCN: Voice changes, speech disruptions, and functional stuttering as well as language impairments are reported but under-researched in around 56-65% of cases (Barnett et al, 2019).
- Dysphagia: Arounds 21% present with swallowing symptoms (Barnett et al, 2019).

Examples of Condition-Specific SLT Interventions -

Motor Neurone Disease (MND)

- Early SLT input is vital for voice banking, AAC planning, and maintaining patient autonomy.
- Dysphagia management requires timely assessment and interventions such as texture modification and gastrostomy planning.

Parkinson's Disease

- SLTs address dysarthria (disorder with physical production of speech), reduced loudness, and cognitive-linguistic changes affecting conversation, offering resource intensive interventions such as LSVT.
- Dysphagia is common and linked to increased risk of aspiration pneumonia, a major cause of morbidity and mortality.

Multiple Sclerosis (MS)

- Communication challenges include dysarthria, impaired verbal fluency, and cognitive-linguistic deficits that affect everyday function.
- Dysphagia can be early and fluctuating, requiring ongoing monitoring and adaptive strategies.

Huntington's Disease (HD)

- Communication difficulties progress with cognitive and motor decline, requiring AAC and carer communication training.
- Dysphagia management is essential for nutritional safety and quality of life, particularly in advanced stages.

Functional Neurological Disorder (FND)

- SLTs play a key role in differentiating functional speech/swallow presentations from structural or neurological causes.
- MDT involvement (including neuropsychology) is critical for effective management and patient education.

RCSLT Key Points as Aligned with Four Priorities -

1. Person-Centred Care

- Inequitable Pathways: Current pathways for neurology patients are not equitable across Northern Ireland, resulting in a postcode lottery of services and significant health inequalities. This includes speech and language therapy services which vary across the trusts in terms of both access to and provision of. We welcome the acknowledgement of the need for a regional approach to the planning and provision of services across Northern Ireland.
- Complex Needs: SLT interventions, particularly in Augmentative and Alternative
 Communication (AAC) and dysphagia, often require longer and more intensive
 input than other therapeutic interventions. For example, one Parkinson's patient
 has currently received twenty-two sessions and continues to require ongoing SLT
 input. The review must therefore recognise the complex and resource heavy
 nature of SLT input for these patients and ensure the workforce review takes this
 into account.
- **Palliative and End-of-Life Care:** SLTs are essential members of palliative care teams, supporting communication and swallowing towards end of life, and should be involved at earlier stages for advanced care planning, voice banking and discussions around the consideration of alternative feeding.
- **Community Access:** Community services should be prioritised to ensure people live well in their homes and communities, avoiding unnecessary hospital admissions. Yet outpatient models do not consistently meet the needs of patients with progressive neurological conditions who become housebound due to their condition and require home based therapeutic support. The RCSLT agree with the recommendation of the development of local multidisciplinary neurological teams where services can be coordinated and staff can either see patients in clinic or visit their homes as needed.

2. Developing Additional Workforce Capacity

• Workforce Numbers:

The proposed 7.6 WTE SLT posts are insufficient to meet the needs of both acute and community services region-wide. While we welcome the recognition of current underfunding, it is important to note that SLTs are already delivering unfunded services in certain areas. Continued underinvestment risks devaluing the SLT workforce and jeopardising the effective implementation of the proposed plans, for both service users

- and staff, particularly in terms of recruitment and retention. To help attract and retain SLTs, it is essential to invest in undergraduate and postgraduate SLT training, including the creation of dedicated neurology posts to support newly qualified clinicians entering the field.
- We would welcome the opportunity to better understand the rationale behind the proposed 7.6 WTE figure, acknowledging that it was developed in consultation with AHP representatives and Department of Health staff, considering the increasing prevalence of many neurological conditions. For example, members are reporting a significant rise in referrals for FND, yet the report does not reflect the role of SLTs in this area. As the report highlights, FND prevalence is likely to increase as awareness grows. It is therefore crucial that SLT capacity is planned and resourced accordingly to ensure service readiness and continuity of care.
- **Need for Specialist Leadership:** We propose that each trust has one Band 8a Lead SLT in Neurology to provide strategic leadership, coordinate transitions between inpatient and outpatient services, and deliver training and supervision for SLTs on the ground. These posts must be protected and not diverted to other workloads. Structured access to neurology-specific SLT roles and clearly defined career pathways will be vital for building and sustaining the workforce.
- Advanced Practice Framework: The <u>AHP Advanced Practice Framework</u> (2019) must be fully implemented to ensure consistent training, competency development, and career progression for SLTs and other AHPs. In addition, the development of specialist training opportunities and advanced clinical practice roles in both community and acute neurology settings will be critical for meeting increasing service demands and enhancing care quality.

3. Addressing Gaps in Current Services

• Community SLT Provision:

Most patients are currently seen by core community SLT staff, with no required standardisation or specialist rehabilitation available across trusts. Having a Lead Neurology SLT to ensure all community staff are adequately supported and trained in neurological condition rehab and management is essential. Community teams often lack the MDT structure that exists in acute care, leaving SLTs working in isolation. Therefore, we

- welcome the Local Neurological Teams as a necessity to mitigate the risks of siloed working and ensure the best outcomes for the patients.
- Investment is required in community rehabilitation, where current gaps are significant. The forthcoming Regional Community Rehabilitation Framework provides a critical opportunity to embed equitable, personcentred rehabilitation into neurology pathways, ensuring patients receive timely support close to home. Improved use of rapid access models, advice and guidance systems, and digital tools should be complemented by robust AHP workforce planning to deliver proactive, preventative care and reduce reliance on hospital-based services.
- Paediatric-to-Adult Transitions: Although it is mentioned within the report, there is a lack of detail on how a seamless transition from paediatric to adult neurology services will be achieved. This is particularly important for patients with lifelong or progressive conditions who require uninterrupted communication and swallowing support and we would welcome more information.
- **Learning from Stroke/Brain Injury Models:** Community stroke and brain injury teams provide examples of well-functioning MDTs that could inform the design of neurology community services and should be considered.

• FND:

- o There is a significant service gap for patients with FND.
- SLTs are increasingly receiving referrals for FND (often presenting with swallowing or globus symptoms) but cannot effectively manage these patients in isolation without mental health and neuropsychology support.
- FND services must include speech and language therapy as part of an MDT, alongside psychological expertise, to manage patient expectations and deliver effective treatment.

4. Using Current Resources More Effectively

• Optimising Existing Services: Speech and Language Therapists have a key role to play in delivering proactive, preventative, and person-centred neurological care. Effective use of current SLT resources can support earlier identification of communication and swallowing difficulties, reduce unnecessary hospital admissions, and enable timely rehabilitation. Ensuring that SLTs are integrated into rapid access pathways, specialist neurology clinics, and multidisciplinary teams will help optimise patient outcomes and make best use of system capacity. In addition, greater use of outcome measures, such as patient-reported tools and goal attainment measures already embedded in SLT practice, can

contribute meaningfully to monitoring the effectiveness of interventions and guiding service development. Aligning SLT involvement with the recommendations of national bodies such as RCSLT, ABN and GIRFT will help ensure that neurology services are holistic, sustainable and driven by evidence-based practice.

- **Shift to Community Focus:** Neurological patients make up a large proportion of the SLT community caseload. Services need to shift resources and value towards community provision, with sufficient SLTs available to deliver intensive rehab and ongoing support keeping hospital beds for those who really need it. Having the Lead SLT post (in each Trust) will ensure that these community SLTs are adequately trained and supported to offer safe and effective care.
- Inpatient Beds: The proposed expansion of inpatient neurology beds presents both an opportunity and a risk. Without the parallel establishment of dedicated Speech and Language Therapy posts, there is a significant danger that existing SLT capacity will be stretched further, diluting specialist input and undermining patient care. SLTs play a critical role in managing dysphagia and communication impairments, which are common and often complex issues in neurological populations. If not addressed promptly and appropriately, these difficulties can lead to serious complications such as aspiration pneumonia, malnutrition, prolonged hospital stays, and reduced quality of life. To ensure safe, effective, and timely intervention, any new inpatient neurology units must include ringfenced MDT resources, with specific provision for specialist SLT roles. This is essential to delivering high-quality, person-centred care and achieving the outcomes envisaged by the Review.
- **Named Care Coordinators:** We fully support the recommendation for named coordinators these roles are invaluable for ensuring seamless pathways and communication across services.

Communication Accessibility -

There are a significant number of people living in Northern Ireland with long term SLCN. Research indicates that around 10% of the population will be living with SLCN and this number is higher for those living with a neurological condition. We would therefore recommend that all health and social care staff adopt the following free, online training to ensure that all facilities are safe, accessible spaces regardless of disability or difference. The NIFRS is a huge advocate for communication access, having adopted this training and made it mandatory across the region. They have incredible outcomes from staff feeling more able to communicate effectively with the public.

<u>Communication Access UK</u> – 4 short modules (15 minutes each) addressing communication, verbal communication, telephone communication and written communication, offering practical tips for your service.

Conclusion and Recommendations

RCSLT NI urges the Department of Health to:

- 1. Explicitly recognise communication and swallowing needs and SLT provision as central to transforming neurology services.
- 2. Reassess the proposed 7.6 WTE SLT workforce to adequately address increasing demand for SLT services by increasing the number of specialist SLT posts, including dedicated Band 8a Lead roles in each trust and ensure that workforce modelling in the report acknowledges the unique, time-intensive nature of SLT intervention.
- 3. Prioritise equitable access to community-based SLT services, ensuring they are MDT-integrated, standardised, and capable of delivering intensive rehab.
- 4. Include SLT expertise in FND service development, palliative care, and across all neurology pathways.
- 5. Fully implement the AHP Advanced Practice Framework (2019) to build a sustainable workforce with clear career pathways and advanced competencies.
- 6. Ensure robust transition arrangements from paediatric to adult services.
- 7. Ensure that SLCN and dysphagia are explicitly named in the Neurology Services Review and associated implementation plan and standards.
- 8. Advocate for early and sustained SLT involvement across all neurological care pathways, including voice banking, AAC, swallowing management, and cognitive-communication rehabilitation.
- 9. Highlight the long-term cost savings, reduced hospital admissions, and quality of life improvements associated with timely SLT intervention.
- 10. Adopt the free, <u>online communication training</u> to guarantee that all health and social care staff are equipped with the knowledge to ensure their communications are inclusive and effective for all.

References

- 1. Beukelman, D., Fager, S., & Nordness, A. (2011). Communication Support for People with ALS. *Neurological Research International*, 714693.
- 2. Romero-Gangonells, E., Virgili-Casas, MN., Dominguez-Rubio, R., Povedano, M., Pérez-Saborit, N., Calvo-Malvar, N., & Barceló, MA. (2020). Evaluation of Dysphagia in Motor Neuron Disease. Review of Available Diagnostic Tools and New Perspectives. *Dysphagia*, PMID: 32797289.
- 3. Johansson, I. L., Samuelsson, C., & Müller, N. (2019). Patients' and communication partners' experiences of communicative changes in Parkinson's disease. *Disability and Rehabilitation*, *42*(13), 1835–1843.
- 4. Suttrup I, & Warnecke T. (2016), Dysphagia in Parkinson's Disease, *Dysphagia*. PMID: 26590572.
- 5. Mirmosayyeb, O., Ebrahimi, N., Shekarian, A., Afshari-Safavi, A., Shaygannejad, V., Barzegar, M., & Bagherieh, S. (2023) Prevalence of dysphagia in patients with multiple sclerosis: A systematic review and meta-analysis, *Journal of Clinical Neuroscience*, Vol. 108, pp. 84-94.
- 6. Barrera, M, A., (2012) When Words Won't Come Easily, MS Focus Magazine; Symptom Management. Access online <u>Multiple Sclerosis Foundation When Words Won't Come Easily: Understanding and Improving MS Speech and Communication Symptoms</u>
- 7. Rusz, J., Klempíř, J., Tykalová, T. *et al.* Characteristics and occurrence of speech impairment in Huntington's disease: possible influence of antipsychotic medication. *J Neural Transm* **121**, 1529–1539 (2014). https://doi.org/10.1007/s00702-014-1229-8
- 8. Raines, C., Clark, M., & Donohue, C., (2025) Profiling swallowing Safety and Physiology in People with Huntington's Disease, *Neurogastronenterology & Motility*, https://doi.org/10.1111/nmo.70035
- 9. Barnett, C., Armes, J., & Smith, C., (2019) Speech, language and swallowing impairments in functional neurological disorder: a scoping review. *Int J Lang Commun Disord*. 54(3): 309-320. doi: 10.1111/1460-6984.12448.