

RCSLT responds to NICE draft quality standard on rare diseases

19 February 2026

Summary

- The National Institute for Health and Care Excellence (NICE) has recently consulted on a [draft quality standard on rare diseases](#).
- In its response, the RCSLT highlighted the links between rare diseases and communication disability, difficulty, or difference, and difficulties with eating, drinking, and swallowing.
- We also highlighted how speech and language therapists can support people with rare diseases, their families and carers, and other professionals working with them.
- The RCSLT hopes that when published the quality standard is the start of an improvement in access to speech and language therapy for people of all ages with rare diseases.

Detailed response

The RCSLT welcomed the draft quality standard's focus on equitable access, and holistic, coordinated care, but made various recommendations on how the quality standard can be strengthened to make that a reality, including that:

- the quality standard reference [NG205 Babies, children and young people's experience of healthcare](#);
- there is greater emphasis on how speech and language therapists can support people through providing direct care and support, as well as supporting the training of other healthcare professionals.
- information being made available in a format that suits an individual and for adjustments to be made so they can communicate in the way that suits them best - for example, through using augmentative and alternative communication, or British Sign Language;
- the section on diversity, equality, and language includes consideration of an individual's needs for receiving, understanding, and communicating information;
- there may be a need for referral to specialist services, such as social prescribing; and
- speech and language therapists, and other allied health professionals, should be listed in the relevant healthcare practitioners sections.