



Date: 13 May 2026

Response to Consultation: Supporting Children and Young People with Medical Conditions at School

1. Introduction

The UK MPS Society welcomes the opportunity to respond to the consultation on supporting children and young people with medical conditions at school.

We are the national charity supporting individuals and families affected by mucopolysaccharidoses (MPS), Fabry disease, and related lysosomal storage disorders. These are rare, progressive, multi-system disorders which often result in complex and fluctuating medical, physical, cognitive and educational needs.

Children and young people affected by these conditions commonly require coordinated support across education, health and social care systems, alongside regular specialist clinical input. Due to the rarity and complexity of these disorders, families frequently experience inconsistent understanding and implementation of support within education settings.

We welcome the intention of the revised guidance to strengthen support for children with medical conditions within schools. However, we believe it is important that the guidance explicitly recognises the distinct needs of children with rare, progressive and medically complex conditions, whose experiences may otherwise become overlooked within broader definitions of medical need.





2. Recognition of Rare, Progressive and Complex Conditions

A key issue for the families we support is the need for statutory guidance to explicitly recognise rare, progressive and medically complex conditions.

While the guidance refers broadly to medical conditions, implementation within schools often focuses primarily on more commonly recognised conditions such as asthma, diabetes, epilepsy and allergies. As a result, children with rare disorders can experience inconsistent support where schools are unfamiliar with the condition, its progression or the associated practical requirements.

Children with MPS and related conditions commonly experience:

- progressive and fluctuating medical needs
- fatigue and reduced stamina
- mobility and physical access difficulties
- sensory and communication challenges
- cognitive and developmental changes
- frequent hospital attendance and specialist appointments
- reliance on specialist treatments and equipment

These needs often change over time due to the progressive nature of the condition.

We therefore strongly recommend that the statutory guidance explicitly references rare diseases, progressive conditions and medically complex conditions to ensure these children are fully considered within school policies and implementation processes.

Without this recognition, there is a risk that the needs of children with complex rare disorders will continue to be diluted within broader categories of medical need.





3. Progressive and Fluctuating Needs

Children with progressive conditions require support arrangements that are flexible, responsive and subject to regular review.

For many rare disorders, needs may fluctuate significantly from day to day and can deteriorate over time. Educational support, healthcare arrangements and reasonable adjustments may therefore need to evolve throughout a child's education.

We recommend that the guidance explicitly recognises the importance of anticipatory planning for progressive conditions, including:

- proactive review of Individual Healthcare Plans
- planning for likely future changes in need
- preparation for increased mobility, fatigue or equipment requirements
- coordination with specialist clinical teams regarding progression and treatment needs

For progressive conditions, anticipatory planning is particularly important. Schools and relevant services should work proactively with families and clinical teams to identify likely future changes in need and ensure that support arrangements evolve in a timely manner.

This includes planning for potential transitions in educational provision, changes in mobility or communication needs, increasing treatment requirements or periods of reduced attendance linked to disease progression or requirement of surgical interventions.

Delays in adapting support arrangements can have significant consequences for educational participation, wellbeing and family stability.





4. Facilitating Access to Specialist Treatments Within School Settings

We particularly welcome the consultation's focus on access to medication and medical support within schools. However, we believe the guidance should more clearly address the practical facilitation of specialist treatments delivered during the school day.

Some children with MPS and related conditions require regular enzyme replacement therapy (ERT), administered through intravenous infusion over several hours on a weekly basis. These treatments are clinically essential and are often delivered by specialist homecare providers or nursing teams.

Many families report that children miss substantial amounts of education because schools are unable to facilitate treatment delivery within the school setting. This can result in avoidable educational disruption, reduced attendance and social exclusion.

Where treatment can safely be delivered within school settings, children should not experience avoidable barriers to educational participation due to operational or logistical limitations.

We therefore recommend that the guidance explicitly recognises the need for schools to work collaboratively with specialist clinical teams and homecare providers to facilitate access to essential treatments where clinically appropriate.

This may include consideration of:

- appropriate clinical or private spaces for treatment delivery
- safe storage of medication and medical supplies
- refrigeration requirements where necessary
- management of medical equipment
- infection prevention and control considerations
- access arrangements for homecare professionals or nursing staff
- procedures for emergency escalation where required





5. Attendance, Inclusion and Educational Participation

Children with rare progressive conditions frequently experience disruption to education due to treatment schedules, specialist appointments, fatigue and fluctuating health needs.

It is important that medically necessary absence is recognised appropriately within attendance processes and that children are not disadvantaged as a result of essential treatment requirements.

We recommend that the guidance makes clear that schools should distinguish between avoidable absence and clinically necessary absence linked to medical treatment or deterioration.

Schools should also be supported to take proactive steps to minimise educational disruption wherever possible, including facilitating treatment within school settings when appropriate.

For some children with progressive and medically complex conditions, there may be periods where full-time attendance within a school setting is not clinically appropriate or sustainable due to treatment burden, fatigue, medical fragility or deterioration in health.

Where this occurs, it is important that access to education continues through flexible and appropriate alternative arrangements, including home-based or hybrid provision where necessary.

Educational access should not be reduced solely because a child's medical condition temporarily or permanently limits attendance within a traditional school environment.

In addition, children with medical conditions should be supported to participate fully in wider school life, including educational visits, extracurricular activities and social opportunities wherever this can be achieved safely and appropriately.





For children with complex progressive conditions, educational participation should not be viewed solely through the lens of academic attainment or physical attendance.

Access to therapeutic, social and enrichment opportunities can play an important role in supporting wellbeing, communication, engagement and quality of life.

Where appropriate, schools should support reasonable access to activities that promote inclusion and participation, including sensory-based activities, communication support, therapeutic interventions and wider social experiences.

6. Training and Understanding of Rare Conditions

Families frequently report that schools have limited awareness or understanding of rare and progressive conditions.

While schools cannot be expected to have detailed knowledge of every rare disorder, they should be supported to work collaboratively with specialist clinicians, nursing teams and patient organisations to develop appropriate understanding and confidence.

We therefore support guidance that encourages:

- condition-specific training where appropriate
- involvement of specialist clinical teams in healthcare planning
- recognition of parental expertise regarding daily management needs
- clear communication pathways between education and healthcare professionals

Families also report that recommendations from specialist clinical centres are not always implemented consistently within education settings, particularly where schools or local systems are unfamiliar with rare conditions or uncertain about responsibility for provision.





The guidance should reinforce the importance of giving appropriate consideration to specialist clinical advice when developing and reviewing healthcare arrangements for children with medically complex conditions.

7. Multi-Agency Coordination and Accountability

Children with medically complex rare conditions often require coordinated support across multiple services, including schools, specialist NHS centres, community nursing teams, homecare providers and local authorities.

Families frequently report that they become the primary coordinators between systems, creating significant emotional and practical burden.

We therefore support stronger expectations around multi-agency coordination within the guidance, including:

- clear communication between education and health services
- defined responsibilities for implementation of healthcare arrangements
- collaborative planning with specialist treatment providers
- regular review processes involving families and clinical teams

Families also report that delays in support and implementation are sometimes linked to uncertainty or disagreement regarding funding responsibilities between education, health and local authority services.

For children with rare and medically complex conditions, this can create delays in the delivery of reasonable adjustments, specialist support or treatment-related provision within education settings.





The guidance should support clearer accountability and collaborative decision-making between services to ensure that children are not disadvantaged by disputes regarding commissioning or funding responsibility.

8. Impact on Families

Families caring for children with progressive rare conditions already manage substantial clinical, emotional and practical responsibilities.

Where schools are unable to accommodate medical needs appropriately, families may experience:

- increased stress and administrative burden
- disruption to employment and family life
- repeated need to advocate for reasonable adjustments
- avoidable educational disruption for the child

Improved clarity, consistency and coordination within the statutory guidance would help reduce these pressures while improving educational access and inclusion.

9. Conclusion

The UK MPS Society supports the ambition of strengthening support for children and young people with medical conditions within education settings.

We strongly recommend that the revised statutory guidance:

- explicitly recognises rare, progressive and medically complex conditions
- supports anticipatory and flexible healthcare planning





MPS Society

Society for Mucopolysaccharide Diseases
MPS House, Repton Place
White Lion Road, Amersham
Buckinghamshire, HP7 9LP, UK

0345 389 9901
mps@mpssociety.org.uk
www.mpssociety.org.uk

Facebook: [@mpssociety](https://www.facebook.com/mpssociety)
Instagram: [@mpssocietyuk](https://www.instagram.com/mpssocietyuk)
LinkedIn: [MPS Society UK](https://www.linkedin.com/company/mps-society-uk)

- facilitates access to specialist treatments within school settings where clinically appropriate
- strengthens collaboration between schools, healthcare providers and families
- improves understanding of fluctuating and progressive conditions
- supports inclusive educational participation and minimises avoidable absence
- recognises the importance of flexible educational provision where full-time school attendance is not always possible
- improves accountability and coordination between services where complex provision is required

Without explicit recognition of these issues, there is a risk that children with the most complex and rare medical conditions will continue to experience inconsistent support and avoidable barriers to education.

The UK MPS Society remains committed to working collaboratively with government and stakeholders to ensure that the needs and experiences of children with rare diseases are fully reflected within future policy and guidance.

