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
Instagram: @mpssocietyuk
LinkedIn: MPS Society UK

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SEND Reform Consultation Response (England)

“Putting Children and Young People First”

1. Introduction

The UK MPS Society welcomes the opportunity to respond to the SEND Reform consultation, *“Putting Children and Young People First”*.

We are a national charity supporting individuals and families affected by mucopolysaccharidoses (MPS) and related lysosomal storage disorders. These are rare, progressive, multi-system and often life-limiting conditions requiring coordinated input across education, health and social care.

As a voluntary sector organisation, we are not responsible for the operational delivery of education services. Our response therefore reflects the experiences of our members and our role in representing children and young people with rare and complex conditions.

Our response is informed by a recent UK MPS Society survey of parents and carers in England.

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2. Evidence from our members

Our recent SEND survey highlights significant systemic challenges:

- 50% experienced delays in assessment
- 62.5% experienced delays in EHCP development
- 87.5% experienced delays in implementation of agreed support

- 50% reported a very negative experience of joint working between education, health and social care
- Only 12.5% felt meaningfully involved in decision-making

Families also described:

- EHCPs not being implemented even when agreed
- school-based removal of support due to cost pressures
- fragmented communication between services
- parents acting as the primary coordinators across systems
- lack of understanding of rare and progressive conditions in education settings
- significant emotional and practical impacts on family life, including employment disruption and stress

These findings reflect a system that is often slow, fragmented and overly reliant on families to coordinate care and educational support.

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3. Core principle: recognising rare and complex conditions

A central issue for our members is the need for SEND reform to explicitly recognise rare, progressive and medically complex conditions within any definition of “complex needs”.

Children with MPS and related conditions commonly experience:

- progressive and fluctuating medical needs
- multi-system involvement across health, education and care
- cognitive, physical and developmental challenges
- reliance on specialist clinical teams
- limited local professional familiarity due to rarity

Any future SEND framework must ensure that definitions of “complex needs” are sufficiently robust to include children with rare and progressive conditions, and that these needs are not diluted within broader categories.

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4. Co-production and the role of families

Our survey shows that only a small proportion of families (12.5%) feel meaningfully involved in decision-making. For children affected by rare conditions, parental expertise is essential to understanding daily needs, risks and disease progression.

We therefore strongly advocate for:

- genuine co-production of EHCPs and support plans
- recognition of families as equal partners in decision-making
- meaningful involvement from the earliest stages of assessment
- access to independent advocacy where required

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5. System fragmentation and implementation failure

A key theme from our members is the failure to implement agreed support consistently and in a timely way.

Despite statutory plans being in place, families report:

- significant delays in implementation
- inconsistent delivery of provision
- repeated need for escalation or appeal
- reliance on parents to coordinate services and challenge decisions

This places substantial emotional and practical strain on families already managing complex medical care.

SEND reform must therefore focus not only on assessment and planning, but also on delivery, accountability and enforcement of agreed provision.

6. Multi-agency working and coordination

Families consistently describe fragmented systems across education, health and social care, with poor communication and unclear accountability between services.

Families also report that collaboration between agencies is frequently hindered by disputes over funding responsibilities. This can leave children and families caught between services while decisions are made about which system should fund particular elements of support.

Families described particular concern where recommendations from specialist clinical centres were not given appropriate weight due to uncertainty around funding responsibility or commissioning arrangements. For children with rare and progressive conditions, this can result in significant delays to necessary provision.

Coordinated working is essential for children with rare conditions due to the multi-system nature of their needs.

We therefore support:

- stronger statutory multi-agency coordination
- clearer accountability across systems
- named key worker models for children with complex needs
- improved communication pathways between services

7. Flexibility of support across levels

Children with rare and progressive conditions require the ability to move flexibly between levels of support as their needs change over time.

However, our members report that the system is often rigid, leading to delays in escalation and gaps in provision.

We support a system where support is:

- needs-led rather than stage-led
- responsive to progression and deterioration
- able to move efficiently between universal, targeted and specialist provision

Escalation should be timely and informed by appropriate specialist clinical input where required.

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8. Educational provision beyond school settings

For some children and young people with rare, progressive and complex conditions, mainstream or specialist school settings may not always be appropriate or sustainable. As needs evolve, attendance in a formal education setting may become increasingly difficult due to medical fragility, fatigue, behavioural changes or clinical risk.

It is essential that the SEND system recognises that education is not synonymous with school attendance. Where a school placement is no longer suitable, high-quality educational provision must continue outside of school, including in the home or alternative settings, without delay or reduction in entitlement.

Such provision should:

- be tailored to the child or young person's medical and developmental needs
- be flexible and responsive to fluctuating health
- ensure continuity of learning, interaction and stimulation
- be coordinated with health and care support

Failure to provide appropriate alternatives risks children becoming effectively excluded from education despite having statutory plans in place.

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9. Anticipatory planning

Anticipatory planning is particularly important for children with progressive conditions. Transitions, including changes in placement, reduced school attendance or moves to home-based provision, should be planned proactively rather than reactively, with input from families and relevant clinical specialists.

Planning should:

- identify likely future changes in need
- ensure provision is in place before transitions occur
- minimise disruption to the child and family
- avoid gaps in support during periods of clinical deterioration

For progressive rare conditions, delays in adapting provision can have significant consequences for educational access, wellbeing and family stability.

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10. Non-academic provision

For children with complex needs, outcomes should not be measured solely through academic attainment. A broader, holistic approach is essential to support wellbeing, engagement and quality of life.

Access to therapeutic and enrichment activities should be recognised as a core part of educational provision, including:

- hydrotherapy
- music therapy
- sensory-based interventions
- communication and interaction-focused activities

These interventions play an important role in:

- promoting enjoyment and emotional wellbeing
- supporting communication and social interaction
- maintaining physical function and comfort
- enabling participation and engagement

Such provision should be embedded within EHCPs where appropriate, rather than treated as optional or supplementary.

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11. Clinical expertise and evidence-based decision-making

For rare and complex conditions, educational decisions must be informed by appropriate clinical expertise.

We therefore strongly support:

- routine involvement of relevant medical specialists in complex cases
- integration of health and education evidence within planning decisions
- engagement with patient organisations where specialist condition knowledge is required

Local systems should also ensure that specialist recommendations are appropriately recognised and incorporated into decision-making processes.

12. Impact on families and wellbeing

The system failures identified in our survey have a significant impact on family wellbeing.

Families report:

- high levels of stress and emotional burden
- exhaustion from navigating fragmented systems
- disruption to employment and financial stability
- distress caused by delays or lack of support

For children with progressive conditions, delays in support can also directly affect health, development, participation and quality of life.

Improving coordination, implementation and consistency is therefore essential not only for educational outcomes, but also for family wellbeing and safeguarding.

13. Conclusion

The UK MPS Society supports the ambition of SEND reform to improve outcomes, consistency and coordination for children and young people.

We strongly recommend that reform must:

- explicitly recognise rare and complex medical SEND within definitions of need
- embed genuine co-production with families as standard practice
- strengthen implementation and enforcement of agreed support
- improve multi-agency coordination and accountability
- ensure timely access to specialist clinical expertise
- ensure that education can be delivered flexibly beyond traditional school settings where required
- recognise holistic and non-academic provision as integral to outcomes for children with complex needs

Without these changes, there is a risk that children with the most complex needs will continue to experience delays, inconsistency and inequitable access to support.

The UK MPS Society remains committed to working collaboratively with government and stakeholders to ensure that the voices and needs of children with rare conditions are fully reflected in future SEND reform.