SMS FOUNDATION UK
Supporting SMS families for a positive future

Statement on Access to Specialist Mental Health and Social Care Support for Individuals with Smith-Magenis Syndrome (SMS)

The SMS Foundation UK provides this statement to support understanding of the mental health and social care needs of children and young people with Smith-Magenis syndrome (SMS). Individuals with SMS frequently require access to specialist services such as Child and Adolescent Mental Health Services (CAMHS), Adult Mental Health Services, and Children with Disabilities (CWD) teams. However, access to these services is often impacted by limited awareness or misunderstanding of the complexity, behavioural presentation, and risk associated with SMS. This statement is intended to provide clear clinical and contextual information to support referral, assessment, and decision-making, and may be used by families and professionals as supporting evidence when seeking appropriate support.

Smith-Magenis syndrome is a rare, complex neurodevelopmental condition caused by a deletion or mutation on chromosome 17. It affects multiple body systems and has a profound impact on behaviour, emotional regulation, mental health, sleep, cognition, and daily functioning. While SMS is commonly associated with a learning disability, the profile is highly variable. The majority of individuals have a learning disability that typically sits within the moderate range, but there are also individuals with mild learning disability, and some with no significant cognitive impairment.

This variability places individuals with SMS at particular risk. Intellectual ability is often not aligned with emotional development. Emotional regulation and emotional maturity in individuals with SMS functions at a significantly lower level than cognitive ability and frequently does not progress beyond an estimated developmental age of around 7 to 12 years. This mismatch is a core feature of the condition and is a key driver of the behaviours that present significant challenge.

Individuals with SMS commonly experience severe emotional dysregulation and complex behaviours, which may include:

- Self-injurious behaviours
- Physical and verbal aggression
- Extreme impulsivity
- Highly controlling or oppositional behaviours
- Significant anxiety and distress

A substantial proportion of individuals with Smith-Magenis syndrome receive additional neurodevelopmental and mental health diagnoses. These commonly include autism

spectrum condition (ASD), attention deficit hyperactivity disorder (ADHD), demand-avoidant profiles (often described as pathological demand avoidance), oppositional and defiant behaviour profiles, and obsessive or compulsive patterns of thinking and behaviour.

These presentations are widely recognised as part of the Smith-Magenis behavioural phenotype and should not be viewed as separate or competing explanations, but as overlapping and compounding needs within a single, complex neurodevelopmental condition.

Children and young people with SMS require access to clinicians and practitioners who have the expertise to assess, support, and treat highly complex neurodevelopmental and behavioural needs. Early and appropriate intervention is critical. Without timely support, behaviours can become entrenched, escalating in frequency, severity, and risk, and becoming far more difficult to manage over time.

The impact on families cannot be underestimated. Many families living with SMS are under sustained and extreme pressure. For some, everyday activities such as eating out, accessing community spaces, using public transport, or travelling through busy environments like train stations and airports are not possible due to the level of risk and distress involved. Families often experience social isolation, exhaustion, and ongoing crisis management across home, school, and wider society.

Access to CAMHS and CWD teams can be the difference between a family receiving essential, preventative support and reaching a point of complete crisis, where coping is no longer possible and risks escalate for both the individual and those around them. Denial of access based on narrow thresholds or misunderstanding of SMS fails to reflect the reality of need and places individuals and families at significant risk.

It is the clear position of the SMS Foundation UK that individuals with must have equitable access to specialist mental health and disability services that reflect the true complexity of the condition. Recognition of emotional development, behavioural risk, family impact, and the importance of early intervention must sit at the heart of assessment and decision-making. Without this, children, young people, and their families are being left without the support they urgently need.