

TRANSFORMING CHILDREN AND YOUNG PEOPLE'S MENTAL HEALTH PROVISION: CONSULTATION.

RESPONSE TO QUESTION 16:

The prevalence of young people with SEN/disabilities must be accurately recorded. Unfortunately, many schools do not accept less visible illnesses, including the chronic neurological disease ME as a disability, despite government confirming that people with ME have “protected characteristics” under equality legislation.

- Many children with ME are referred to CAMHS, which can be accurately recorded.
- School absence can be accurately recorded. In ME, this is due to faulty energy metabolism- inability to regenerate energy expended. School attendance is thus a key cause of relapse. There can be devastating consequences for children and families if schools do not understand this disability. Many are too unwell to attend school; one in four is house and/or bedbound. ME is the biggest cause of long-term sickness absence (Dowsett and Colby, JFS, 1997, and others)
- A significant number experience co-morbid anxiety and distress from coping with the burden and stigma ME and educational pressures.

It is imperative to:

- Understand that some young people with SEN/disabilities need to access support services in a way that is appropriate for their level of functionality
- Test access to services through various methods, including consulting with existing and new service users, putting appropriate support in place to enable them to do so, and using communications channels appropriate for their needs and preferences
- Work with suitable partners (eg. disability charities) to ask how their beneficiaries access support and what barriers they experience to doing so
- Consult with families as to the suitability of provision.