

1. Action for M.E. is the UK's leading charity for children and adults affected by Myalgic Encephalomyelitis (M.E.). We take action to end the ignorance, injustice and neglect faced by people with M.E. We do this by meeting need now to improve the lives of people with M.E. while taking action to secure change for the future. Alongside providing information, support and advice to children and adults to help improve their health and well-being, we work with professionals to enhance the care and support that people with M.E. receive, and fund research projects to advance knowledge of the illness.

2. M.E. is a chronic neurological condition that causes symptoms affecting many body systems, commonly the nervous and immune systems. M.E. affects around 250,000 people in the UK, of which 25,000 are children and young people. People with M.E. experience severe, persistent fatigue associated with post-exertional malaise (the body's inability to recover normally after expending any energy), causing a flare-up in symptoms including chronic pain. There is a spectrum of severity: around one in four people with M.E. are so severely affected that they are unable to do any activity for themselves, or can carry out minimal daily tasks only.

3. Our evidence to this inquiry is based on:

- a survey conducted through May to June 2018 to inform our response to this specific inquiry
- the experiences of children, young people and families affected by M.E. who contact our Information and Support services.

Recommendations

4. Action for M.E. recommends that:

- Assessors of SEND support to recognise children and young people with long-term health conditions such as M.E. within the SEND group, consistent with the definition of disability under the Equality Act 2010
- Support provided through SEND to focus on what steps can be taken to enable any child to meet their individual needs, regardless of the nature of their impairment
- SEND support staff to consult with professionals from different sectors and with specific expertise as required, to ensure they understand and adequately support the ways in which children and young people are affected by their SEND
- Schools to be required by the Department for Education to publish their medical conditions policies online.

Assessment of and support for children and young people with SEND

5. M.E. affects 1 in 100 young people [Crawley, Emond and Sterne 2011] and has been found to be the leading cause of long-term school absence [Dowsett and Colby 1997]. This can be due to symptoms such as post-exertional malaise, where the body is unable to recover normally after expending energy, and cognitive dysfunction. The effect this can have on a child's peer network and their feelings of isolation is profound. While in some cases a child may be unable to take part in school due to their health, in others it may be possible that with the right support they can continue to attend, perhaps only part-time, which could reduce the social and educational impact of their condition. Therefore, SEND support can be vital in recognising how M.E. impacts on a child's ability to participate in school, and taking active steps to reduce these barriers.

6. However, one common problem that children and young people with M.E. face is a lack of understanding from professionals. In our 2017 survey, 96% of families told us that a lack of

understanding of M.E. negatively impacted on the support they receive, and 90% felt that the professionals involved with their child did not believe them [Action for M.E. 2017]. This means that, where a professional does not understand or believe in the impact of M.E., the opportunity to tackle the barriers preventing the child's participation in school is lost. Therefore, despite the need for SEND support, we hear of mixed experiences from families who are trying to secure appropriate provision.

7. One reason is that the professionals responsible for assessing children and young people do not see M.E. as a relevant condition that comes under the umbrella of 'SEND'. For example, one parent said:

"The school don't see M.E. as a SEND and despite being off school since January 2016 we've had no involvement with the SENCO. We've applied for a post-16 EHCP which they're a bit bemused about"

8. This demonstrates how individual professionals can affect whether a child receives appropriate support, based upon their understanding (and sometimes, misconceptions) of the way in which the child is affected by either Special Educational Needs or a disability. This particularly is an issue for M.E. As mentioned earlier, many professionals, even in the health and care sector, as well as in education, do not understand M.E. and can therefore miss opportunities to support children and young people with the condition. For example, another parent said:

"They haven't officially assessed her although we've asked. They think she is just too tired to go to school and don't see this as SEND"

9. To ensure that children with M.E. have a chance to secure appropriate SEND support, education professionals must understand the condition and how it affects someone's capabilities. If a professional has not had prior experience of a condition, it is their responsibility to find out more through research, consultation with the voluntary sector, or with professionals from other disciplines (such as health and care).

10. In a related point, children and young people with M.E. can be refused support on the basis that SEND is seen as a narrow range of conditions. One parent said *"[the school] do not consider CFS/M.E. as an educational need, despite an attendance percentage of 16%"*. We heard from a number of young people who were told that they were "too bright" to receive support for a SEND:

"We received no support from the school, they did as I asked but kept saying she was bright she didn't need support. She did at the time. They refused extra time for exams as they said exam boards didn't give it although I knew of many other people who got it. All I heard all the time is she is bright"

"Assessment process must be able to capture conditions with symptoms and impact of M.E. who are of high intelligence"

11. This suggests that there is a focus on children and young people who have special educational needs, and how they can be supported. While they may be in the majority, it is also necessary that staff are equipped to support those with a wide range of disabilities and long-term health conditions that impact upon their ability to take part in education. The symptoms of M.E. commonly affect how a child can take part in school, yet too often staff *"do not think there are any SEND needs to assess"* (parent of a child with M.E.) However, many long-term conditions are considered as disabilities under the Equality Act 2010, including M.E. To facilitate better support for children and young people with M.E., and other

conditions, schools should publish their medical conditions policy online. This would enable parents and young people affected by M.E. to understand the support on offer, and facilitate their communication with the school to secure this support. The positive impact that achieving appropriate support can have is demonstrated by one young person who said:

“Have time to sleep in college, wake and rest breaks. Use a wheelchair get pushed. Have almost full time 1:1. College have been fantastic in helping me and helping me to manage this condition”

12. For another example of the positive impact of good practice, a video on Action for M.E.'s Youtube channel explains more about the [right support at school](#).

13. One common theme from families affected by M.E. is that any SEND support they receive has been hard-won. Parents of children with M.E. already have to navigate a number of complex issues, due to the needs of their child, as well as take on additional caring responsibilities. Having to advocate, when SEND teams are intended to specialise in disability support, only adds to these extra pressures. Parents have told us:

“As the parent I needed to be vigilant and ensure accuracy of terminology (they still couldn't get their heads around 'variable' functional ability)”

“School did not believe my son's illness at all. It was a constant battle in primary having to constantly educate attendance officer, head teacher and class teachers. Then my son moved up to high school and it happened all over again”

14. One young person said:

“My mum had to drive the process which took over two years. SENCO at school were awful and spent more time arguing with home tuition service than getting things done”

15. These instances demonstrate that individual circumstances greatly influence the support that children and young people receive. Whether it is having an understanding support at school, or a parent who can vocally advocate for their child's needs, the variability in the experiences of people with M.E. show that it is not systematically included as an aspect of SEND in schools.

The roles of and co-operation between education, health and social care sectors

16. We hear of mixed experiences from families with M.E. of the extent to which the education, health and social care sectors co-operate successfully. This is in spite of the positive effect it can have on support for the family. One person said:

“SEND team forced the school to communicate better with them and me, but never with medical staff. The communication I did have was beneficial to feeling supported and also removed some of the pressure put on me by the school as they realised it was out of their hands and in control of the SEND team”

17. In this submission we have highlighted that the experience of children and young people with M.E. varies widely, both in relation to the support they receive and the individual co-operative practices of professionals. The need for collaboration is particularly acute in cases where individual professionals are not meeting the needs of the child. Where SEND staff face a disability or condition that they are not familiar with, or do not know how to support, they have a duty to reach out to others to inform their perspective.