

Written evidence submitted by The WellChild Charity to The Children's Wellbeing and Schools Bill Committee (CWSB266).

WellChild is the national charity for children with complex medical needs and their families. More than 100,000 children and young people are living across the UK with complex medical needs. Many spend months, even years in hospital simply because there is no support enabling them to leave. Meanwhile those who are at home face inconsistent and inadequate levels of support. Through a nationwide network of children's nurses, garden transformation projects and family support services, WellChild exists to give this growing population of children and young people the best possible chance to thrive: properly supported at home, together with their families.

We have surveyed our network of parent carers to get their opinions and concern about the new Children's Schools and Wellbeing Bill. We had 191 responses to our survey. We are submitting evidence because many of our parent carers were deeply concerned about the implications that this Bill may have on their families and the risk that it brought to children with complex medical needs. The concern raised by our parents, which will be addressed in our written evidence consisted of:

- Worries that their child would be forced back into a school environment which would harm their wellbeing
- Concerns about the expanse of power of LAs to refuse the request of parents to take their children out of SEN schools
- Concerns about the negative impact of having to fill out extensive documentation
- Privacy and data concerns
- Concerns over home visits
- Vague wording of the bill
- Issues that have failed to be addressed by the bill
- Issues with the speed of the bill and the input being gathered from it

1. Parents negative experiences of the current school system

Education in school cannot always meet the needs of children, particularly for children with complex medical needs. This may be due to lack of provision or funding as the child's needs are too complex, and the school environment being unsuitable as a result. Parents also reference the challenges experienced when trying to work with LAs and schools when a child is struggling in the school environment. Below are some of the responses shared in our

survey demonstrating the reasons why parents have chosen to home educate their child. There were many other responses of a similar nature.

"My eldest has Ehlers Danlos and when she was at school, despite having letters from the specialist, the school didn't believe us. At six years old her symptoms really progressed and the school kept telling her she was making it up. By the time I decided to deregister her, she was so physically unwell and depressed from bullying by the teachers. The problem with Ehlers Danlos is that it is a hidden disability and many of the symptoms match abuse type flags. For example, bruising and injuries due to clumsiness, or chronic fatigue and not looking to thrive. Through home education, she was able to do learning at a pace that suited her, take regular breaks in a comfortable environment and I focused on building back her self-esteem back up. If we had continued with school, I honestly don't think she would be here now. She was suicidal and the waiting list for CAMHS was two years. If the bill goes through and ultimately parents can't choose to remove their child from school, how can we keep our children safe?" Survey respondent.

"I have an 11-year-old child with a brain tumour and brain injury from surgery and hydrocephalus. He suffers with uncontrollable chronic pain. He could not cope in school. He was distressed all the time. He was not able to stay in the classroom to learn. He was almost impossible to get to school which caused a lot of upset and violent meltdowns at home. The teachers and I would have to drag him through the gates if I could get him there in the car. I can't believe I went along with this for so long. He is now home educated. He has a bespoke education with a 1 to 1 (mum) he can rest when he needs to which enables him to be ready to learn. He is also being assessed for autism. The school environment is not at all suitable for him. He is now able to access museums and galleries and public swimming pools at quieter times, so he is able to begin enjoying his life again. We study as much as he can manage each morning and attend groups for socialising and exercise in the afternoons. I would like to apply for an EHCP for him in case he ever wants to try to access a more formal education as he would need to attend a SEN school. However, I am reticent to do this in case it might affect his rights to home education." Survey respondent.

"My daughter has a complex medical condition. She spends a great deal of time in hospitals or at doctors' appointments. Home is her sanctuary, her safe place. Intrusion and judgement on our home when it actually bears so little relevance to the home education, she experiences would be traumatic and harmful. School did not meet her needs, and in fact neglected some of her most basic ones. She has been on diuretics her whole life and was denied access to the toilet leading to her wetting herself. She was frequently made to miss snack due to not finishing her work, despite needing regular high calorie snacks for her medical needs. Her neurodivergent needs were ignored and blamed on her medical issues." Survey respondent.

These examples highlight that school education is not always in the best interest of the child and emphasises the need for parents to have the option to home educate their child so that they are able to meet their needs.

Families also highlighted the benefits of homeschooling their child including:

- Enabling them to give their child an education that is specifically tailored to their individual needs
- The positive impact of home education on family's wellbeing as some children with complex health needs will have a significantly reduced lifespan and therefore having children in the home to make the most of the families limited time together can be invaluable.
- The fact that the child's health should be placed above their educational needs.

As a result, the restriction that the Children's Wellbeing and School Bill places on parents' ability to home educate their children poses a significant threat to the wellbeing of children with complex medical needs. Many parents are concerned that this bill would force their child back into school, which cannot sufficiently cater to their needs and remove an alternative profession that they describe as a 'lifeline' that helps enable them to access a more personalised form of education based on the child's needs and ability.

2. Concerns about the expanse of power of LAs to refuse the request of parents to take their children out of SEN schools

Parents are deeply concerned about the qualifications and experience of assessors evaluating SEN children and home education environments. They fear unqualified assessors may unjustly send their children back to school, disregarding the parents' expertise and understanding of their child's needs. The opinion of the parent should also take precedence as they are the expert in their child and understand their needs the best.

Local Authorities (LAs) may have conflicting interests, such as financial incentives (for example cheaper for a SEN child to remain in school) to keep SEN children in school, potentially prioritising these over the child's best interests. There is also a perception of bias, with some believing the government inherently favours school education for all children.

A significant lack of trust in LAs exists, with parents feeling that LAs often do not act in the child's best interest and that there needs to be measures in place to hold LA decisions to account. Legislation is already in place to cover safeguarding, yet it is not being implemented properly. This raises concerns about how this new legislation may be abused or neglected.

Parents worry that this new legislation could increase risks for SEN children. Parents raised concerns that an unfounded safeguarding concern (e.g. raised by an unhappy teacher or an abusive ex-husband) could result in a child being returned to school).

Families may be less inclined to apply for an ECHP or send their child to a SEN school in the first place (even if that is what is best for them) in case it prevented them from being able to deregister their child from school in the future.

The absence of a clear appeal process for challenging LA decisions to return children to school is also troubling for parents.

Recommendations:

1. Children attending a SEN school should not be included in the list of conditions for obtaining permission from the LA as this is likely to unfairly discriminate against children with additional needs
2. Legislation should make it obligatory for the professional making these decisions to be properly qualified in both SEN and home education.

3. Concerns about the negative impact of having to fill out extensive documentation

Parents reported that the obligation to fill out excessive documentation and paperwork to homeschool their children would be detrimental to parents and families that are already under strain and penalise them further. Parents with children with complex medical needs are already low on time and overloaded with a significant amount of bureaucracy. The additional burden of having to fill out detailed forms about every aspect of their child's education would place an additional and potentially unmanageable strain on these parents. Additional stress on the parents is also likely to have a negative impact on the child and the parent's ability to deliver what they need.

"I don't have time to give all the information they want for this register. As a parent of two children with additional needs, there is no extra time or energy. I cannot time every learning experience or report every person who teaches my child something." Survey respondent.

The additional time required to complete this paperwork could also take valuable time away from both the care and education that parents provide.

Parents are concerned about potential discrimination due to the requirement to obtain additional information from clubs, groups, and activities. They fear many places may stop offering home education activities to avoid fines and extra administrative work, or that their children may be excluded from activities because coordinators lack the capacity to handle the additional requirements. This is seen as unfair, as children in school attending the same activities would not face these demands. The increased effort and paperwork may discourage families from participating in home education groups, leading to further isolation, especially for children with complex medical needs who already face challenges accessing groups.

There are also concerns about the lack of clarity on how LAs will assess the adequacy of home education environments. The vague legislation could allow LAs to misuse their power and deem home education environments unsuitable without sufficient reason.

Recommendations:

1. Require a lower initial amount of information, expanding only if concerns arise. This approach would be more manageable and prevent unnecessary disruption to families successfully home educating.
2. Ensure the bill is not misinterpreted or applied heavy-handedly by some authorities.

4. Privacy and data sharing concerns

Parents are concerned about the security of their information if required to report detailed data to the LA. They fear that detailed information about their child's whereabouts and contacts could pose a safeguarding risk if leaked, potentially exposing children to abuse or trafficking. Previous breaches of information in the public sector have eroded trust in LAs' ability to keep this information secure. One parent shared their experience: *"Our local authority has shared other families' details with us on multiple occasions. I do not want them to have any more sensitive data, especially in cases where domestic violence is present."* Survey respondent.

Parents are worried about the fact that despite the significant risk to children's data there is no independent data protection/ privacy impact assessment.

Recommendation:

1. The register should only include basic information about children, avoiding excessive details that could pose privacy concerns.

5. Concerns over home visits

The overwhelming majority of our families felt that home visit would be intrusive and cause additional trauma to children and their families. Many parents referenced homes as their child's 'safe space' and highlighted the potential negative impact on their wellbeing and mental health were this safe space to be removed. Many of these children have suffered trauma from their experiences at school and strangers invasively entering their home could set them back in their progress or have a detrimental effect on their wellbeing due to the

stress of the situation. Additionally, neurodiverse children are likely to not be able to cope with having strangers in their home and the negative impact on their wellbeing and the stress that this situation could cause should be considered.

Home visits could also pose a physical health threat to children with complex health needs who are more susceptible to illness than other. One parent noted: *“Under the bill we wouldn’t have the right to refuse an LA officer visit to our home - even if they turned up with an obvious cold or during a period of illness. On that basis our education provision would be judged as inadequate and a SAO issued. Basically, signing my daughter’s death warrant.”* Survey respondent.

Some are also concerned that allowing more people into the home can inflate potential risks for safeguarding and cause detriment to the child as they are strangers to them. One parent noted that: *“Safeguarding and wellbeing concerns allowing strangers into my home our home is our safe place would cause massive anxiety to my children it's the one place they know they can be themselves without judgement and the whole point of home educating is so my children can be confident in what they’re doing in a safe and supportive environment home checks will take that security away from them.”* Survey respondent.

Recommendation:

1. LAs should not have the power to conduct home visits.

6. Vague wording of the bill

The wording of the bill remains vague on several points with could leave much open to the interpretation and opinion of assessors. These points need clarifying:

- There should be specific guidance about what parents need to report.
- The criteria for evaluation should be explicitly and precisely stated.
- Any detail missing from the bill should be added in at this stage as leaving it till a later point risks families being further disadvantaged.

7. Issues that have failed to be addressed by the bill

This bill is overly focused on mainstream and fails to sufficiently consider SEN children or to cater to individual needs. The bill does not address the real issues of inadequate SEN provision in schools and over stretched social services. It fails to recognise the very different needs of children who have experienced trauma, illness or any other differences. Additional funding and support should be directed towards SEN children.

Provision for before/after school clubs also don't go far enough to enable complex children to attend. Families who may already be eligible for respite cannot access this, as they do not cater for complex needs. There needs to be more done for complex needs to make activities inclusive.

Furthermore, the bill does not specify how it's going to support safeguarding of children in schools with regards to bullying, violence and harassment through both peers and teaching staff.

There are concerns that the measures laid out in this bill will be expensive (such as creating a register) and that this money will be directed away from essential services when it should be being used to help children.

8. Issues with the speed of the bill and the input being gathered from it

The rapid progression of this Bill through Parliament, coupled with the lack of accessible information, has made it difficult for the core individuals affected by this legislation to provide evidence. Consequently, this group has been excluded from contributing their perspectives.

The rushed timeline for the Bill's introduction has severely limited opportunities for meaningful consultation, amendment, or reflection. This hasty process raises concerns that the Bill could be poorly thought-out, potentially resulting in unintended harm to children and families, thereby undermining its own objectives.

Furthermore, it is unclear whether the Bill has received input from professionals in the education sector and those working in SEN schools. Have children and young people been consulted? It is crucial that all these voices are heard.

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