Which children and young people does the Children and Families Act apply to and why is important for the NHS?

The Children and Families Act is introducing a new system of support for children and young people with special educational needs and disabled children and young people between 0 and 25. It places duties on clinical commissioning groups, NHS England, NHS Trusts, NHS Foundation Trusts and other health bodies to co-operate and make arrangements to support.

Definitions

Special Educational Need:

A child or young person has special educational needs if they have a learning difficulty or a disability requiring special educational provision.

A child has a *learning difficulty* if they:

a) have a significantly greater difficulty in learning than the majority of their peers,
or

b) have a disability which means that they can't access the type of facilities generally provided for others of the same age in mainstream education institutions; or find it very difficult to access them.

A child under compulsory school age has special educational needs if it likely that they will be classed as having a learning difficulty or disability when they reach school age.

For a child under two special educational provision means educational provision of any kind.

Around 1.7m children or 20% of school aged children have a special educational need.

Disability:
The Children and Families Act uses the Equality Act 2010 definition of disability.

Disability is defined as a physical or mental impairment that has a *'substantial'* and *'long-term'* negative effect on the ability to do normal daily activities. This definition will include a range of impairments, diagnoses and long term health conditions including:

- Sensory and physical conditions
- Cognitive and learning disabilities
- Acute and long term medical and life limiting conditions.
- Emotional, social and behavioural disorders
- Communication difficulties

There are 0.8 million disabled children and young people aged 0 – 18 in the UK, 6% of all children. The NHS has to make reasonable adjustments for disabled children and young people under the Equality Act 2010 where they would otherwise be at a substantial disadvantage compared with non-disabled children and young people.

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The group of children and young people affected by this legislation include children and young people with complex health needs. Comorbidities frequently occur in this group and individual children and young people may need to access a range of health treatment, medicine and support from different specialists working in provider organisations secured by different commissioners, including services in:

- Primary Care
- Community
- Acute Hospitals
- Specialist Centres and hospitals.

This complex web of provision can lead to a failure to deliver person centred care with the holistic needs and wishes of the child, young person and their family being overlooked in the response to their various health needs.

Why is the Children and Families Act Necessary?

Health outcomes for disabled children and young people and those with special educational needs (SEN) are significantly poorer than in the general population. This continues into adulthood. They are also more likely to experience material disadvantage.

- Children and young people with SEN and disability are more likely than others to live in poverty
- They are more likely to live with a parent who is also disabled
- They are more likely to be more socially isolated.
- They are more likely to experience barriers to education, leisure or play
- They are more likely to have mental health problems
- They are more likely to have additional physical health problems, such as being overweight
- Children in socio-economically disadvantaged households in early childhood are twice as likely than the least disadvantaged children to develop a disabling condition in later childhood
- 97% of adults with learning disability have a long term health condition
- For children and young people with a learning disability, the prevalence rate of a diagnosable psychiatric disorder is 36%, compared with 8% of those who did not have a learning disability

In addition children and young people with SEN and disability and their families face a number of additional barriers that can have a negative impact on their life experiences and outcomes

These barriers include:

- unsuitable or inaccessible environments,
- discriminatory social attitudes and
- discriminatory institutional practices.

The Children and Families Act is an opportunity for health services in each local area to evaluate how they meet the needs of this group of children and young people and how they can work with education and social care services to meet their statutory duties to reduce health inequalities.

CCGs and NHS England need to think about how they can improve their health outcomes in line with their statutory responsibility for taking action to reduce health inequality.

Children and young people with SEN and disability have the same aspirations and life goals as other children and young people. They want fulfilling childhoods and then to pursue their aspirations into adulthood. However to achieve this "ordinary life" those with special educational needs and disability will often require support from education, health and social care services.

However these services are designed and delivered by different sets of specialist staff and providers working in different systems with different priorities. These systems and priorities don't always align with each other and gaps may develop between the different systems. This can generate serious problems for children, young people and their families when trying to get the support they need.

The challenges that children and young people with Special Educational Needs and disability face in getting the appropriate support from health, education and social care can have a negative impact on both children and young people's health outcomes and also on their parent and carer's wellbeing. These have been well documented in a number of key reports in recent years, including the 2 reports of the Children and Young People's Health Outcomes Forum, The Chief Medical Officers Report and the Kennedy Review of Children Services.

These highlight how, across a range of indicators including; quality of life, school absence, secondary mental and physical health problems, personal autonomy and involvement in further education and employment, children and young people with SEN and disability do not achieve the outcomes that the system should support them to achieve.

Issues in current system of support across education, health and social care.

The most significant problems in the current system of support are:

1. **Too many children with SEN and disability have their needs identified late:**

Early identification of impairments and health conditions can mean that services can put specialist care in place at an early stage. However pathways to diagnosis are not developed, not clear and not coordinated between different services. There is also a lack of understanding of and investment in early intervention in health services for disabled children and a lack of coordinated support for families focused on prevention and management. Parents report long delays in the diagnostic process and a lack of coordinated support following a diagnosis for wider issues like sleep, behaviour and eating.

There is also a significant issue of young people with learning disabilities being at an increased risk of mental health or behavioural problems but these needs are not picked up or addressed by services.

2. Significant gaps between different services both within health and across health education and social care:

Currently there is too often a lack of shared vision between different professionals across services and the family they are working with regarding the outcomes that they are trying to achieve. Different services work in silos, treating children and young people's individual health needs separately with insufficient integration of support. There are frequent disputes over the responsibility for provision of services between commissioners that result in provision not being available at all or not available at the right time.

The result is families often have to take responsibility for engaging with and coordinating services themselves but there is frequently an accountability regarding the delivery of services, often with no clear means of redress when for families that have been failed by the system.

This has a negative impact on children and young people in terms of less long term stability, happiness and poorer management of long term conditions.

3. Services not listening to children, young people and their families when putting support in place

Different families need different support for different needs and their voice is crucial to understanding what support would work best for them. Many families with children and young people with SEN and disability have to deal with wider discrimination or lack of support networks. Families of disabled children are also more likely to have related needs around poverty and housing that have a significant impact on their health that are not addressed. This can be compounded by physical and institutional barriers that can prevent access to universal services, including leisure facilities. This can lead to a concentration on "specialist" services that reduce opportunities for whole family activities and wide ranging social interactions.

Impact of these Problems

These problems can create situations that are very distressing for children, young people and their families.

> *"It's a mystery to me how the whole thing works to be quite honest. For some things, one agency makes a decision. For other things, three agencies seem to have to be involved. It seemed like I was on the 'phone or writing letters and emailing every minute of every day. Everyone treating my daughter was behind us, the services here were waiting to admit her, but the PCT was not responding to emails or phone calls. It took six months and it has remained a mystery why there was such a problem."*
> **Mother of a disabled teenager**

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The Opportunity of the Children and Families Act

The Children and Families Act is an opportunity for the health service in each local area to evaluate how they meet the needs of children and young people with SEN and disability, including how they can work with education and social care services.

The importance of responding to this challenge has been recognised as a priority area for the NHS. The NHS Mandate and the NHS England Business Plan both contain clear objectives for improving outcomes for children and young people with SEN and disability and this is built on by the Better Health Outcomes for Children and Young People Pledge that has been signed by the key stakeholder in the health system.

It is CCGs and NHS England need to think about how they can improve their health outcomes, in line with their statutory responsibility for taking action to reduce health inequality.