

Legal Rights and Protections for Children and Young people with Hyperinsulinism in education. Notes taken from Steve Broach (KC Barrister) presentation for The Children's Hyperinsulinism Charity's Family Conference 2023:

Children and Families Act 2014: new legislation brought in to reform the system in relation to children and young people with special educational needs and disabilities.

To view the Children and Families Act go to the gov.uk website for the official text of the legislation. Check with the green bar that comes up, that it is the latest version available.

Part 3: of the Act concerns children and young people with special educational needs or disabilities.

What does it mean to have special educational needs?

Section 20: When a child or a young person* has a learning difficulty or a disability and that learning difficulty or disability calls for special educational provision to be made for them.

**A young person, under the Children and Families Act is essentially someone aged 16 to 25.*

Definition of 'learning difficulty or disability':

A learning difficulty is a significantly greater difficulty in learning than the majority of others of the same age. It may well be that a child with Hyperinsulinism, has that significantly greater difficulty in learning and so therefore can come into that gateway.

They may also have a disability, which for this purpose means a disability that prevents or hinders them, so makes it more difficult for them, to make use of mainstream facilities so you may well come in as a child with hyperinsulinism under 2(b) here as having a disability.

What does Special educational provision mean?

Special educational provision is defined in section 21 of the Act. Special educational provision for a child aged two or more, or a young person, so anyone aged over two, means educational or training provision that is additional to, or different from, that made generally for others of the same age in mainstream schools in England.

In order to have a learning difficulty or disability that calls for special educational provision you must need provision that's additional to, or different from, that made generally in mainstream schools or nurseries or colleges across the country.

So to have special educational needs it means that you have some kind of impairment or difficulty, which calls for (requires) additional provision to be made. Importantly for young children any requirement for educational provision for those under two amounts to special educational provision.

This section also defines other important concepts first of all healthcare provision because that means anything that you can get under the NHS, and then social care provision is anything made by a Local Authority in the exercise with Social Services function. So, there are three separate ideas here special educational provision, health care provision and social care provision.

Section 21, Subsection 5, healthcare provision or social care provision which educates or trains, a child or young person is to be treated as special educational provision instead of health care or social care. This means that things that would normally be understood to be health or social care are magically transformed into educational provision, for the purposes of the Children and Families Act.

Most obviously things like speech and language therapy, occupational therapy, physiotherapy. Anything which has the effect of educating or training, the child or young person, is going to become educational provision, so that means that it would go in section F of an EHC plan, and it would be the responsibility of the local authority to deliver it not the NHS.

So that's what's called a 'deeming provision' Section 21(5) takes things that would ordinarily be understood to be health or social care and makes them educational provisions.

Section 19: the general principles that must apply in everything that a Local Authority does. Under the Children and Families Act a Local Authority must have regard to various things.

'have regard' duties mean the local Authority must think about something, they must take something into account, technically it's a mandatory relevant consideration. Doesn't mean they have to achieve that thing, or do that thing, it means they have to consider and take account of that thing, which is powerful and important, but does have limits, because they can consider it and still not do it.

Section 19 is relevant in terms of shaping the way that Local Authorities are supposed to carry out their functions. So, the things they have to think about, have regard to, are the views wishes and feelings of the child and his or her parent or the young person. So, families are supposed to be absolutely at the centre of anything done under the Children and Families Act.

The importance of the child and parents or young person participating, as fully as possible, in decisions related to that function and having the relevant information and support necessary to enable participation in those decisions. So the idea of proper participation 'nothing about us, without us', is absolutely central to delivery of this scheme for children with hyperinsulinism for any other child with special educational needs.

Section 19 (d) is slightly different it says that local authorities have to think about the need to support the child and parent or the young person in order to facilitate the development of the child and young person and to help them achieve, the best possible educational and other outcomes. Now that's important phrase because one of the aims of the Children and Families Act was to shift away from process to outcomes.

Education, Health, Care Needs Assessment:

The gateway to getting any entitlement to additional support under the Children and Families Act is an EHC needs assessment. The SEND code of practice outlines a concept of SEN support with a four-part cycle of assessment, planning, delivery and review and schools are given delegated budgets to deliver that kind of support.

However, there's nothing about that in the Children and Family Act itself it's all from the Code of Practice. You don't have any statutory entitlements until you get to the stage of requesting an Education, Health, Care Needs Assessment. That request can be made to the Local Authority by

the child's parent, the young person, or a school or college, and unsurprisingly it's an assessment of the Child and Young Person's Educational, Health and Social care needs.

The test for when does the local Authority have to carry out an EHC Needs Assessment is in **subsection 8**. The local Authority must, (when legislation uses the word 'must' that means it's a duty rather than just a power to do something) so they must secure EHC Needs Assessment, if after having regard to people's views and the evidence, the authority is of the opinion that, (so it's a question of judgement for the Local Authority) the child or young person has or may have Special Education Needs.

When might it be necessary for the child or young person to get their education through an EHC plan? If they might want or need to go to a specialist school, because apart from for limited periods of assessment, every child at a specialist school needs to have an EHC plan. So that's a good answer to that question.

If the child is clearly going to go to and stay at a mainstream school, then the question really becomes about the nature and extent of the provision they might require, and if that provision is the kind of provision that could ordinarily be expected to be made by a school within their budget of £6,000 a year, the notional budget, then the Local Authority will be entitled to say no and we're not going to do an EHC Needs Assessment because the school should be meeting these needs.

However, £6,000 a year isn't a lot of money, and it goes very quickly, if a child might need any significant amount of teaching assistance support, or might need significant therapeutic input, it could well be the case that they're going to need an EHC plan and that duty on the Local Authority to secure additional provision. So, at this stage the test is simply *that it may be necessary, that there's a realistic possibility, that the child might need an EHC plan.*

If you are refused the EHC Needs Assessment it's well worth taking advice from an organisation like IPSEA or SOS SEN or other support organisations, or from a lawyer, as to whether or not you can appeal that decision to the tribunal, on the evidence that's available.

So that's the EHC needs assessment process. After the assessment, the Local Authority will decide, whether to issue an EHC plan for the child and we see that the test here, is whether in the light of the needs assessment it is necessary, for special educational provision to be made in accordance with an EHC plan.

So instead of it being a realistic possibility threshold, we're now at the stage of on balance, because everything in this area of law is decided on balance of probabilities. On balance it's going to be necessary for special educational provision to be made in accordance with the EHC plan. If you meet that threshold then you get an EHC plan.

Why are EHC plans so important?

Section 42 imposes a 'specific duty', on the Local Authority and a specific duty is one that's owed to individual children and young people and can be enforced by way of judicial review. So if a local Authority breaches a specific duty then that child or young person can go to the high court and ask a high court judge to order them to do what the plan says, and that's why the section 42 duty is so important, it's not owed generally to a population of children, it's owed to

the individual child, or young person, and we see that because the section applies where a local Authority maintains an EHC plan for a child or young person and it says the Local Authority must secure the specified special educational provision.

So that means **anything in section F of the EHC plan must be secured at all times**, and then if, the plan specifies healthcare provision, the responsible commissioning body, which will generally be the ICB the Integrated Commissioning Board must arrange the specified Healthcare provision. In my view there's no legal difference between those two terms here, the reason that the local Authority must secure it and that the ICB must arrange it is because ICB's only commission, whereas some local authorities still provide some services themselves. So that's the explanation for the difference in language, but the legal effect is the same, it must be done, for the child or young person at all times.

The other important entitlement that it gives, is to go around the entire school admissions process, because any school or institution of these types that is named in an EHC plan must admit the child or young person so that's maintained schools, academies, non-maintained special schools or any independent sector schools that are on the secretary of states approved list under Section 41 of the Act.

Sometimes Local Authorities will say ' we can't name you the school around the corner because they've said they can't meet Johnny's needs', that's not right it's for the Local Authority to decide whether or not they can meet the child's needs. The school will give a view and the local Authority can decide whether to accept that or not. If the Authority says that they're not going to name the school, the parents will have the right to appeal to the tribunal. It's important to keep in mind that the tribunal, in our area is a very powerful legal tool, because it stands in the shoes of the Local Authority. It doesn't review the lawfulness of decisions in this area, in the same way that the high court does on judicial review, it simply decides for itself on the evidence whether it's right or not that the school can't meet need.

Appeals

These are the things you can appeal under **Section 51**. It will be a requirement to consider mediating before you can appeal to the tribunal and you need to get a mediation certificate to prove that. However, you don't need to go through a mediation process, you can appeal to the tribunal without going through mediation.

- the refusal to assess
- the refusal following an assessment to issue a plan
- the contents of the plan, in relation to the education parts.
- You can also ask the tribunal to make recommendations about the Health and Social care aspects of the plan.
- Refusal to reassess, a refusal to amend a plan following an annual review, because EHC plans must be reviewed annually. Children's needs change and if the local Authority says no, we think the plan's fine as it is, then you can appeal to the tribunal to get it changed, or if they try and change it you can appeal against that to the tribunal

- the decision to cease to maintain the plan. EHC plans run out eventually at or around a Young Person's 25th birthday but a local Authority may decide to cease to maintain it much earlier because they say it's no longer needed, that the educational outcomes have been achieved, and if they do, do that then the parent can appeal to the tribunal.

Very importantly if the issue that you have isn't in this list you can't go to the tribunal, the tribunal has no jurisdiction and so that's why judicial review is such an important part of the legal talk here, because you will see that one of the things you can't appeal about is the Local Authority isn't doing what my EHC plan says.

The tribunal has no power to enforce the contents of the plan at all so if you've gone to Tribunal, for example, and got this all singing and dancing EHC plan that properly reflects your child's needs and has all the necessary provision in, as the law requires, and then the Local Authority doesn't do it, you need to know that there's another stage, that you can go through.

You can of course use the complaints process, but it may be that it's so urgent and important that judicial review is the appropriate remedy and that of course is something on which people would need advice.

Regulations: Parliament gives the 'headlines' in an Act of Parliament, the detail will be fleshed out in regulations, or rules, or other forms of secondary legislation as they're called. So, the SEND regulations Special Education Needs and Disability regulations sit underneath the Children and Families act and give more detail, for example, in terms of assessments, things that must be considered when deciding whether special educational provision may be necessary.

The contents of an EHC plan are set out in the regulations. We can see that when preparing an EHC plan in regulation 12 here, the Local Authority must set out the views, interests and aspirations of the child and parents, or young person.

- Section A, has no legal effect but clearly it is important that the plan accurately records who the child of young person is, what the parents think, and so on.
- Section B, special educational needs
- Section C healthcare needs that relate to their special educational needs
- Section D social care needs
- Section E outcomes
- Section F special educational provision required
- Section G healthcare provision
- Section H social care provision, which is split between sections H1 and H2*

*That's because the Chronically Sick and Disabled Persons Act (CSDPA) which creates the duty to secure the social care provision only applies to children. Adults get their social care input under the Care Act and not all disabled children will qualify for support under the CSDPA. So, if you're a child you want the provision written here into section H1, and if you're a child and it goes in H2 there may be some question as to whether you're actually going to get it.

If you're an adult, then you want it to be clear that the Care Act mandates the provision of this social care.

In relation to social care, an EHC plan does nothing more than just record what the child or young person may be entitled to, under other legislation, so it doesn't really change the position very much at all.

Children with Medical Needs

An important section of the Children and Families Act. That's the duty in relation to children with medical needs and that's in section 100 of the Act. It is in part five, the welfare of children.

Section 100 the duty to support people with medical conditions. Now that's going to be centrally important of course, to children with hyperinsulinism and we see that the duty is that the appropriate Authority for the school, essentially the governing body, or the proprietor of the academy, the management committee of a PRU, must make arrangements.

So, there's a duty, but it's a duty to make arrangements for supporting pupils in the school with medical conditions. So, a broad overarching duty. A general duty, because we see it's about making arrangements for supporting pupils, plural, at the school with medical conditions. So, it doesn't say the school must meet the needs of every pupil with medical conditions in the school. **What they have to comply with in this duty, is appropriate arrangements in place, and importantly in meeting the duty in this subsection the school must have regard to guidance issued by the Secretary of State.**

Children with medical needs but no special educational needs / do not require special educational provision:

These children won't have anything to do with the Children and Families Act. They won't get an EHC plan they, won't even get an EHC needs assessment because it's not realistically possible they're going to need an EHC plan.

For these children you want this statutory guidance: **Supporting pupils of medical conditions at school.** Statutory guidance means it's issued under an Act of Parliament. So, you have to look at the Act of Parliament and see what it tells you to do with the guidance. We know from section 100 that this is guidance that schools have to have regard to, that means they have to consider it.

Therefore, it may be that if they wanted to depart from it, they'd have to have good reason to do so, because it is such clear and authoritative guidance. However, it doesn't have the highest legal force that guidance can have, which is guidance that Local Authorities and Schools have to act under, but it's still a very important document, as it is set out to be the statutory guidance that everyone in English schools should follow.

Pupils at school with medical conditions should be properly supported, so that they have full access to education, including school trips and physical education.

That sentence alone is a really good start, so what that's essentially saying is don't discriminate against pupils with medical conditions at school. Don't treat them less favourably, make sure

they have full access to education, that word **full** is really important, that means the same access as their peers.

Now the delivery of that education may need to be different, to take account of their conditions, but they should be getting the same benefit as their age peers essentially. We know governing bodies must ensure arrangements are in place. Then this is important as well, governing bodies should ensure that school leaders consult Health and Social Care professionals, pupils, and parents to ensure that the needs of children with medical conditions are properly understood and effectively supported.

So the guidance is saying don't just put your arrangements in place, make sure you've actually worked with children and families and relevant professionals, to understand what is needed and then of course it goes on and gives a lot more detail about what precisely is going to be needed in any particular case.

I want to mention, that the guidance describes a document that is going to be of significant importance to many children with hyperinsulinism the **Individual Health Care Plan** sometimes shortened to an IHP. So, a governing body *should*, should is pretty good, it's not quite as good as must, but certainly has a mandatory effect, ensure that the school's policy covers the role of individual health care plans, who's responsible for their development in supporting pupils at school with medical conditions, and they should be reviewed at annually, should be developed with the child's best interests in mind etc.

Then we get the further advice about the detail, what the plans should contain their format and so on. That's important, there is a strong expectation at the very least, that every child with significant medical needs will have an IHP in school and importantly where a child does have an EHC plan, the IHP should be linked to, or become part of the EHC plan.

The guidance is also helpful, to solve the problem families also face of being past from pillar to post with the Local Authority saying it's the school's job, school saying it's the ICB job etc. Here it sets out roles and responsibilities:

What Local Authorities should do: So Local Authorities are commissioners of school nurses for maintained schools and academies and under Section 10 of the Children Act 2004 which is a very important underpinning piece of legislation, that tells a range of bodies to co-operate in terms of promoting Children's Welfare. They must collaborate with their partners with a view to improving the welfare of the children, And Local Authorities and now ICBs of course, it used to be CCGs, must make joint commissioning arrangements.

Section 26 they should provide support, advice and guidance to ensure that support specified within IHP's can be delivered effectively. So, although they don't have the same legal force as EHC plans there's definitely again this expectation that the IHP will be an important document.

Where pupils will not receive a suitable education in a mainstream school because of their health needs the local Authority has a duty to make other arrangements. Now that's a reference to section 19 of the Education Act 1996 which we will look at in the education part of the talks.

Since 2013 local authorities have been responsible for commissioning school nursing, but this does not include clinical support for children in schools who have long-term conditions and disabilities which remains an ICB commissioning responsibility.

So, if there's a very unfortunate argument going on about who's going to support and pay for additional clinical support in schools the answer, says this guidance, is it remains an NHS responsibility, even though general school nursing is now the responsibility of Local Authorities. I think that's quite an important point to flag.

Equality Act:

The Equality Act is quite an elegant piece of legislation in many ways, it takes a series of protective characteristics (we're focusing on the characteristic of disability), it prohibits lots of different people from doing various things in relation to those protected characteristics, but it also for the protective characteristic of disability, imposes positive duties to make reasonable adjustments. So, it's about making the world a better place for many of our children and young people not just about prohibiting negative treatment, negative discrimination.

The Equality Act is in various parts, some key parts for our purpose, services and public functions so **Section 29** of the Act tells service providers and also anyone not a service provider but exercising a public function here, that they mustn't discriminate.

You may need section 29, but section 29 only applies where none of the other parts are in play, and for our purpose parents may well be very interested in the part around work, but we're going to be particularly interested in **part 6 and education**.

There are obligations imposed on schools, FE colleges, higher education colleges, qualifications bodies, and so on.

In terms of schools it's **Section 85** *responsible bodies of schools must not discriminate in terms of admissions, in terms of the provision of education, affording the people access to a benefit, facility, or service, not providing education, exclusions etc.*

Essentially any other area in which that they might treat a person in a way that is prohibited and there's also, prohibitions on harassment and victimization as well. **So that's the duty on schools essentially don't breach the Equality Act in relation to disabled children.**

For our purposes the definition of disability in section six:

A person has a disability if they have a physical or mental impairment. So I would suggest by definition any child with hyperinsulinism has a physical impairment so we're almost certainly going to be getting through that gateway.

Then this is the question, *does that impairment have a substantial and long-term effect (adverse effect) on their ability to carry out normal day-to-day activities.*

Substantial means more than 'minor or trivial' again very likely to be yes. Long-term means at least 12 months again, yes.

So, if I add up all the various bits of this jigsaw it's quite difficult for me to think of a child who will have a diagnosis of hyperinsulinism who isn't disabled under the Section Six definition.

Now that might be news to people it may well be that the context of the idea of disability and Disability Rights isn't yet central to the community, I think it should be because, these are really important protections, really profound legal protections, and just because the group of children we're concerned with today aren't traditionally thought of as being disabled children. If they meet the definition then they are, as a matter of law.

A Whistle Stop tour through what are people not allowed to do taking schools as our example in relation to disabled people. So, the different forms of prohibited conduct.

Direct discrimination: A person discriminates against another if because of a protected characteristic they treat them less favourably than they treat or would treat others e.g. you can't come to my school because you have hyperinsulinism. To make out direct discrimination you've got to prove a causal link between the disability and the treatment, because of disability the person's treated less favourably so that's quite hard, what is more likely I would suggest, is discrimination arising from:

Section 15 so a person discriminates against a disabled person if they treat them unfavourably because of something arising in consequence of their disability and they can't show the treatment as a proportionate means of achieving a legitimate aim. So, to get through this firstly you would have to show that you've been treated unfavourably e.g. denied access to a school trip, denied access to the school, because of something arising in consequence of your disability which might be your health needs for example for other cohorts of disabled children it might be their behaviour so it's anything that you can show arises in consequence of your disability.

If you're treated unfairly because of that reason again you got to have a causal connection, then you get through that gateway. Then it comes from the school to show that what they've done is a proportionate means of achieving a legitimate aim. There are a host of legitimate aims, health and safety is a legitimate aim, essentially it just has to be a lawful and a reasonable one, but what's really important is that *what's being done is proportionate to that aim.*

So, that allows the court or the tribunal to get into the question of 'well, why couldn't this child go on the school trip?' or 'why couldn't they have access to the same education as their other peers are getting?' Therefore, it is a powerful scrutiny tool i.e. a school has to provide evidence to support the fact that this thing can't safely be done or reasonably be done.

indirect discrimination when you have a general PCP (Provision, Criterion or Practice) e.g. a uniform policy for example, behaviour policy, and if that applies to everyone and puts (in our case), children with hyperinsulinism at a particular disadvantage compared to others then again that will be discriminatory unless the school can show that it's a proportionate means of achieving a legitimate aim. So, this captures all those kinds of unintended forms of discrimination or unfavourable consequences for disabled children,

The duty to make reasonable adjustments. In relation to schools, it's the first and third requirement that apply here.

The first requirement again, relates to this idea of PCP Provision Criterion or Practice.

So, if there is a rule that's putting a disabled person, (so a child with hyperinsulinism) at a substantial disadvantage then the school must take such steps as reasonable to have to take, to avoid the disadvantage. So, all policies must flex and bend to take account of this duty

The third requirement is a requirement where a disabled person would but for the provision of an auxiliary Aid be put at a substantial disadvantage. To take steps, to provide the auxiliary Aid and we know from lower down this section that **auxiliary aids include services, and those services include people, so that's why schools may have a freestanding obligation to put in place additional support, additional facilities, additional staff in order to avoid disabled children being put at a substantial disadvantage i.e. missing out on a school trip, not being able to take part in PE, whatever it might be, and bear in mind that this has nothing to do with the EHC plans this is a completely separate set of obligations owed to a different but overlapping group of children because we're talking here about disabled children as opposed to children with special education needs.**

This is the most powerful, most important of the obligations, because it's saying to schools (and applies to a range of other bodies as well). It's not good enough to leave things as they are, you have to make changes to the way you do things (under the first requirement), to what services and support you provide (under the third requirement), in order to make the world a more accessible place for our children.

So, a combination of potentially an EHC plan, almost certainly an Individual Health Plan, and the Equality of duties for children with hyperinsulinism, are a very useful set of legal protections that our families can use both in terms of conversations with schools and other bodies but also if necessary, in the courts as well.

Judicial Review:

Steve Broach's blog called Rights in Reality: <https://rightsinreality.wordpress.com/> has a list of solicitors, (not recommendations and not comprehensive), that specialise in this area and there's also a link to my page where I explain what judicial review is.

<https://rightsinreality.wordpress.com/2014/09/13/solicitors-with-expertise-in-disability-and-sen-cases/>

The list on the blog shows solicitors and specified those you can access legal aid, but also links to various support and advice organisations.

Legal Aid: sometimes legal aid will be assessed based on the child's means alone and therefore many children and families will qualify, other times the parents means are taken into account that will make it much harder to get legal aid. The legal aid scheme is complicated and thankfully, as a barrister I don't have to operate it so I refer you to my colleagues and the solicitors firms. If you get legal aid, and it's appropriate then legal aid will also extend to barrister's advice and representation in appropriate cases as well. So most of my cases and certainly the ones that make the law reports in the High Court will be funded by legal aid.

So a practical point to end, if you are concerned, then get advice. It may be that the advice is that you can go to the tribunal in which case you can either do that yourself, or with support from one of these organisations or from a solicitor, but you may well have to pay for that, if it's not an issue that can go to the tribunal then the remedy, the legal remedy, is going to be judicial review you'll need advice about whether that's appropriate, or whether you need to use the complaints process instead, because you can't essentially do both, there has to be a reason why you choose one or the other ,you would need individual advice about that.

Steve Broach KC: Year of call: 2008 Silk: 2024

Steve is a public lawyer with particular expertise in health, education and social care and disability and children's rights cases. He is a discrimination specialist and has acted in many of the leading public law discrimination cases. Steve is instructed in the High Court and above in applications for judicial review, the Court of Protection for cases involving the Mental Capacity Act 2005 and the First-tier and Upper Tribunals in education and other appeals.

Steve is co-author of Disabled Children: A Legal Handbook (Legal Action Group) and is an editor of the Community Care Law Reports. He previously worked in the voluntary sector in senior roles relating to disability and children's rights.

The Children's Hyperinsulinism Charity would like to express our gratitude to Steve Broach for providing us with his expertise and time resulting in such a valuable resource for the children, young adults and families we support.

- These notes are taken from the recording of Steve Broach KC, SEN Barrister at The Children's Hyperinsulinism Charity's conference in 2023. These notes have been prepared by Trustees of the Charity and are designed to be a helpful handout to go alongside the video. However, for accuracy and exactness please refer to Steve Broach's spoken presentation in the video.
- The video and handout are for the use of The Children's Hyperinsulinism Charity and specifically for the children, young adults and families we support. The information in parts, is tailored to meet the needs of individuals with Hyperinsulinism.
- The video and handout should not be edited or amended, including screenshots.
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