

The Rights of Disabled Children

Northern Ireland Children's Law Centre 2019

Lady Hale, President of the Supreme Court

12 April 2019

Let's begin with some ringing declarations. Article 26 of the Charter of Fundamental Rights of the European Union declares that:

‘The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.’

Article 24 deals with the rights of the child and includes:

‘1. Children shall have the right to such protection and care as is necessary for their wellbeing. They may express their views freely. Such views shall be taken into consideration on matters which concern them in accordance with their age and maturity.

2. In all actions concerning children, whether taken by public authorities or private institutions, the child's best interests must be a primary consideration.’

So, how well are we doing in respecting the rights of disabled children? There are many different types of disability and children with disabilities come in all sorts of shapes and sizes. They are all individuals and the problems they face – including their legal problems – also come in all sorts of shapes and sizes. But the legal problems they have encountered, at least in Great Britain, seem to fall into three broad categories.

First, there are the difficulties in accessing the public services they need, often now brought about by the severe pressures on funding for local government services. The High Court in England has heard several cases challenging the legality of local authorities' decisions to cut funds for children's social and educational services. In *R (DAT and BNM) v West Berkshire Council* [2016] EWHC 1876 (Admin), (2016) 19 CCLR 362, five disabled children challenged the Council's decision drastically to reduce funding for short breaks, many of them provided by voluntary organisations, to help their carers to be able to carry on providing care for them. In *R (KE) v Bristol City Council* [2018] EWHC 2103 (Admin), (2018) 21 CCLR 751, two disabled children and one mother challenged the Council's decision drastically to reduce the funding available for educational services for children with special educational needs. And in *R (Hollow) v Surrey County Council* [2019] EWHC 618, five disabled children challenged the Council's budget, which identified special educational needs as an area in which cuts might be made.

These challenges were based on failures to comply with certain specific statutory duties under legislation which applies in England (and sometimes in Scotland and Wales as well) but not in Northern Ireland (although there may be some equivalents). Relevantly:

- (i) The public sector equality duty in s 149(1) Equality Act 2010 to have due regard to the need to (a) to eliminate discrimination against disabled persons which is prohibited by the Act; (b) to advance equality of opportunity between disabled and non-disabled persons; and (c) to foster good relations between disabled and non-disabled persons. There is an equivalent to (b) in section 75(1) of the Northern Ireland Act 1998.
- (ii) The duty of certain public authorities, including local authorities (but not most of central government), under s 11(2) of the Children Act 2004, to have regard to the

need to safeguard and promote the welfare of all children when discharging their functions. This is much wider than the duties towards children in need under our Children Act 1989 and the Children (Northern Ireland) Order. But there may be something approaching this in section 1 of the Children's Services Co-operation Act (Northern Ireland) 2015.

- (iii) The duty of local authorities in England, under section 27 of the Children and Families Act 2014, (1) to keep under review the educational, training and social care provision for children who have special educational needs or a disability, (2) to consider to what extent to which it is sufficient to meet the needs of the children concerned, and (3) to consult a wide range of people and bodies, including the children in its area with special educational needs or disabilities and their parents. Something similar is to be introduced into the Education (Northern Ireland) Order 1996 by section 2 of the Educational Needs and Disability Act (Northern Ireland) 2016 but not yet in force.
- (iv) In the *West Berkshire case* there were also some very specific duties, under the Breaks for Carers of Disabled Children Regulations 2011 (SI 707/2011), so far as practicable to provide a range of services sufficient to assist carers to continue to provide care or to do so more effectively. We have not found any Northern Ireland equivalent.

Along with these statutory duties, the challenges relied upon common law duties to act fairly and to behave rationally.

The claimants succeeded in the *West Berkshire case* because the officers had not drawn the councillors' attention to these duties in the report leading to their decision. The claimants also

succeeded in the *Bristol case*, because there were both statutory and common law duties to consult and they had not done so; there was also a breach of the section 11 duty to have regard to the need to safeguard and promote the children's welfare; and they had failed to take into account relevant considerations, meaning that they had acted irrationally at common law. However, the claimants failed in the *Surrey case*, because the Council had not yet identified any cuts to be made in the services provided: the budget was part of a local government accountancy exercise showing how savings might be made but was not yet set in stone. There was nothing yet upon which the Council could consult.

I know that the Northern Ireland Children's Law Centre brings similar cases to try and secure appropriate services for children with disabilities and is sometimes frustrated that the authorities settle them before they have the opportunity to get to court to obtain a ruling establishing the principle.

I'm told that there is also a case pending against the Chancellor of the Exchequer and/or Secretary of State for Education where three disabled children who have had difficulties in accessing appropriate education and support are challenging the lawfulness of the national approach to the funding of provision to meet the special educational needs of children in England. Here too, the claimants are relying on the public sector equality duty, which applies to central as well as local government, and on section 7 of the Children and Young Persons Act 2008. For the first time, this places a 'general duty' on the Secretary of State 'to promote the well-being of children in England', in addition to the existing duty, under section 10 of the Education Act 1996 to promote the education of the people of England and Wales. Whether such duties can translate into concrete legal obligations remains to be seen.

In the second category are challenges to the rules governing welfare benefits for disabled children. These have been based, not on domestic statutory duties, but on the human rights of the children concerned. Two of these have reached the Supreme Court. In *Cameron Mathieson v Secretary of State for Work and Pensions* [2015] UKSC 47, [2015] 1 WLR 3250, a child with very, very severe disabilities challenged the rule which meant that he was no longer entitled to disability living allowance (DLA) once he had spent 84 days in hospital. But his parents were still expected to be with him at all times in hospital and to provide a substantial part of the care which he needed there. This meant that the extra money provided by the allowance was needed to enable them to do so.

In *R (MA) v Secretary of State for Work and Pensions* [2016] UKSC 58, [2016] 1 WLR 4550, a number of challenges to the so-called ‘removal of the spare room subsidy’, otherwise known as the bedroom tax, were grouped together. Two of these involved disabled children. Rian was a child with severe disabilities, a full-time wheelchair user and with other problems, including incontinence. His parent were separated and shared his care. He spent more of his time with his mother but he stayed with his father every weekend and for at least one day during the week and for part of the school holidays. His father had a two-bedroom property, but under the regulations was entitled to housing benefit for only one. Warren, a teenager with profound mental and physical disabilities, required 24-hour care from two people. He had lived with his grandmother since he was a few months old. He lived with her and her husband in a three bedroomed house. Respite care was provided by carers who stayed overnight two nights a week. Without this the grandparents would not be able to cope.

In both the Disabled Living Allowance and the bedroom tax cases, the challenge was based on article 14 of the European Convention on Human Rights. Article 14 provides that the enjoyment of the Convention rights shall be secured without discrimination on any ground

such as sex, race and a long list of other characteristics ‘or other status’. It is not a freestanding right to equal treatment – it is only a right to equal treatment in the enjoyment of the Convention rights. But on the other hand there is no need to show that one of the Convention rights has been breached – otherwise article 14 would add nothing to them.

So there are four questions in article 14 cases:

- (i) Do the facts fall ‘within the ambit’ of a convention right? The right to welfare benefits, even non-contributory or means-tested benefits, is ‘property’ within the meaning of article 1 of the First Protocol (A1P1), so the facts of *Cameron Mathieson’s* case fell within the ambit of A1P1. The right to respect for the home, private and family life is protected by article 8, and the court in the bedroom tax cases treated this as falling within the ambit of article 8.
- (ii) Is the reason, or ground, for the difference in treatment between this person and other persons a ‘status’ for this purpose? Disability is not among the listed characteristics but has long been held to be such a status. So this was not a problem in the bedroom tax cases. In *Cameron Mathieson’s case*, however, it was necessary to decide whether being a disabled child who required more than 84 days of hospital care – or very prolonged hospital care - was a ‘status’ within the meaning of article 14. The Supreme Court decided that it was.
- (iii) Has the person concerned been treated less favourably, on the ground of his status, from someone who is in an analogous situation? In *Cameron Mathieson’s case*, he had been treated less favourably than disabled children who did not require more than 84 days’ hospital care and who therefore remained entitled to their Disabled Living

Allowance. In the bedroom tax cases, the complaint was of a rather different type of discrimination: that they had been treated in the same way as other people, when they should have been treated differently because their relevant circumstances were different. Disabled people who needed an extra bedroom because of their disability had been treated in the same way as non-disabled people who did not need an extra bedroom (this is known as *Tblimmenos* discrimination, after the case of *Tblimmenos v Greece* (2001) 31 EHRR 15).

- (iv) Can the difference in treatment be justified? In other words, do the means chosen bear ‘a reasonable relationship of proportionality’ to the aims sought to be achieved? We usually break this down into four questions; (a) is there a legitimate aim in the public interest; (b) is this a rational or suitable way of achieving the aim; (c) could a lesser measure have been chosen; and (d) overall, has a fair balance been struck between the ends and the means – between the public interest and the rights of the individual? In *Cameron Mathieson’s case*, the difference could not be justified, because his needs were the same however long he had been in hospital. In the bedroom tax cases, the rule could not be justified if there was a ‘transparent medical need’ for an extra bedroom and, in Warren’s case, there was. In Rian’s case, on the other hand, the extra bedroom was required for social reasons which had nothing to do with his disability – the problem would have been the same in all shared care situations, irrespective of disability.

These cases all raise the question of how far the children’s rights under other human rights Conventions were relevant to deciding whether their rights under the European Convention had been breached. Those Conventions give children some pretty powerful rights. The wonderful aspirations of the Universal Declaration of Human Rights of 1948 were eventually translated into binding obligations by the International Covenants on Civil and Political Rights and on Economic,

Social and Cultural Rights in 1966. These don't specifically deal with children or with disabilities, but many of their obligations are relevant to both. More helpful, however, are the later Conventions applying those same principles to the specific case of children and people with disabilities.

Thus, article 2 of the United Nations Convention on the Rights of the Child 1989 (UNCRC) requires that the rights set out in the Convention be respected and secured without discrimination on a number of grounds, expressly including the disability of either the child or his parents. Article 3.1, as is well known, requires that in all official actions concerning children the best interests of the child shall be a first priority. This seems to have been the motivation behind the statutory duties of public authorities, mentioned earlier, to safeguard and promote the welfare of children, although this is not quite the same thing. Article 23 is specifically concerned with disabled children:

‘1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for

employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

...’

The United Nations Committee on the Rights of the Child doesn’t think that the United Kingdom has been doing very well. In their Concluding Observations on our fifth periodic report (June 2016) they say this (para 55):

‘The Committee is concerned that:

(a) Many children with disabilities do not see that their views are given due weight in making personal decisions in their life, including choice of support and future;

(b) Many children with disabilities are still placed in special schools or special units in mainstream schools and many school buildings and facilities are not made fully accessible to children with disabilities;

(c) Provision of the support for transition to adulthood is often neither sufficient, timely nor well-coordinated, and does not ensure fully-informed decision by children with disabilities.’

So they recommend that we adopt a ‘human rights based approach to disability’, set up a comprehensive strategy for the inclusion of children with disabilities and address all the above failings.

The United Nations Convention on the Rights of People with Disabilities 2006 (UNCRPD) has taken the human rights-based approach even further, stressing that people with disabilities have

the same fundamental rights as other people, and some extra rights which are special to their special needs. Article 7 deals with children with disabilities:

‘1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.’

Article 23 deals with respect for home and the family and in article 23.3 requires:

‘States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.’

Article 24 deals with education and requires ‘an inclusive education system’ and lifelong learning directed to ‘the full development of human potential and sense of dignity and self worth’ and ‘enabling people with disabilities to participate effectively in a free society’. Children with disabilities should not be excluded from the general education system, should receive the support they need within the general education system, and there should be reasonable accommodation

for their needs. However, the United Kingdom government has entered a reservation, reserving the right for disabled children to be educated outside their local community where more appropriate provision is available elsewhere. It has also made a declaration that it believes that both mainstream and special schools are allowed under the Convention.

Once again, the United Nations Committee on the Rights of Persons with Disabilities is not very impressed. In its Concluding Observations on the initial report of the United Kingdom (October 2017), they say this (para 20):

‘The Committee is concerned about:

- (a) The lack of a policy framework addressing the poverty of many families with children with disabilities;
- (b) The failure to incorporate the human rights model of disability in public policies and legislation concerning children and young persons with disabilities;
- (c) The lack of monitoring mechanisms and reliable indicators, particularly concerning bullying against children with disabilities in school;
- (d) The absence of a general statutory duty upon public authorities to ensure adequate childcare for children with disabilities;
- (e) The reported increase of incidents of bullying, hate speech and hate crime against children with disabilities.’

So they recommend developing policies to deal with each of these.

Unlike the European Convention, none of these Conventions has been incorporated into UK law, save in very limited respects. But are they relevant to the interpretation and application of the rights under the European Convention, which have been turned into rights in UK law? In *R (SB)*

v SSWP [2015] 1 WLR 1449, the first benefit cap case, the Secretary of State argued that, although an international Convention might inform the interpretation of the substantive Convention rights, it had no part to play in the interpretation of article 14, and thus no role in any inquiry into whether a difference in treatment was justified. But a majority of the Supreme Court rejected that argument, although a different majority held that the UN Convention on the Rights of the Child was not relevant to the discrimination complained of, which was against the women, not the children: the children suffered just as much whether they were living with their mothers or their fathers. In *Cameron Mathieson's case*, the court reached the conclusion that the difference in treatment between Cameron and other disabled children was not justified, without relying on the international conventions. But the majority pointed out that this conclusion 'harmonised' with the conclusion they would have reached under the conventions, as there was no evidence that the Secretary of State had given any thought to the interests of the children involved.

But there's a third category of case, which concerns, not whether disabled children have been discriminated against in the enjoyment of their Convention rights, but whether their substantive Convention rights have been violated. The Supreme Court has one such case before it at the moment. I can explain the issues, although I cannot tell you the answer.

The case of D (on appeal from *In re D (A Child)* [2017] EWCA Civ 1695, [2018] 2 FLR 13) concerns the liberty rights of mentally disabled 16 and 17-year-olds. D has attention deficit hyperactivity disorder, Asperger's syndrome, Tourette's syndrome and a mild learning disability. For many years, his parents struggled to look after him in the family home. Eventually, when he was 13, he was admitted to a hospital which provided mental health services to young people between the ages of 12 and 18. The external door to his unit was locked, he was checked on by staff every half hour, and if he left the unit he would be accompanied by staff on a one to one basis. He was assessed as not being competent to consent to these arrangements.

In 2015, when he was still 15 years old, a High Court judge held that he was objectively confined at the hospital but that his parents could consent to that confinement in the exercise of their parental responsibility. So he was not deprived of his liberty within the meaning of article 5 of the ECHR, which protects the right to liberty. But by then it had been agreed that he was fit to be discharged to a residential placement and arrangements were made for him to be transferred to 'placement B'. The local authority which was looking after him accepted that the regime which he would experience there also amounted to confinement. However, his parents agreed to the placement and to the arrangements. In April 2015, on his 16th birthday, proceedings were issued in the Court of Protection. The local authority sought a declaration that he was not deprived of his liberty within the meaning of article 5, because his parents could consent to the arrangements. The Official Solicitor, on D's behalf, agreed that the arrangements were in his best interests, but argued that he was deprived of his liberty because his parents could not in law consent to them. The Court authorised the placement and he was transferred there in June 2015.

Everyone agreed that the arrangements meant that D was under continuous supervision and control and not free to leave. This meant that they satisfied the 'acid test' of a deprivation of liberty, as decided by the Supreme Court in the case of *Cheshire West*. But a confinement which would otherwise amount to a deprivation of liberty does not do so if the patient has consented to it: see *Storck v Germany* (2006) 43 EHRR 6. I must say that I find this a rather puzzling requirement, as one hopes that even if the person concerned did consent to the arrangements, he or she would always be able to withdraw that consent, thus converting the confinement, if it continued, into a deprivation of liberty. Be that as it may, the High Court judge held that, once D had reached 16, his parents could no longer consent to his confinement, so he was deprived of his liberty for article 5 purposes. The local authority appealed. (D's placement changed in the meantime but nothing else did.) The Court of Appeal held that the parents could consent to the confinement of a 16 or

17-year-old child who lacked the capacity to decide for himself and so D was not deprived of his liberty. The Official Solicitor has appealed on his behalf to the Supreme Court.

This is a really difficult question. In a way it's academic because D has always enjoyed the safeguard of a High Court judge making decisions about his future (and he has now reached 18). But the question is whether any such safeguards are necessary. On the one hand, parents have parental responsibility for their minor children, potentially up to the age of 18. It has long been recognised, both by statute and the common law, that parental responsibility has to yield to the child's growing autonomy. Section 8 of our Family Law Reform Act 1969, and section 4 of your Age of Majority Act (Northern Ireland) 1969, recognise that the consent of a capable 16 or 17-year-old to medical or dental treatment is as good as if he were an adult. And in *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, the House of Lords held that a child under 16 could also give a valid consent to medical treatment if she was competent to do so. Neither the statute nor the House of Lords say in so many words that, once the child reaches competence, the parents cannot override her refusal to consent. But it would logically follow: how can you be competent to say yes but not competent to say no? Allowing a court to override the child's wishes is another matter. Our Mental Health Act 1983, and the Mental Health (Northern Ireland) Order 1986, are to the same effect: a child of 16 or 17 who has the capacity to do so can agree to her own informal admission to hospital for psychiatric treatment. These do spell out that if she does not agree her parents, or anyone else with parental responsibility cannot do so on her behalf (1983 Act, s 131(2) to (4)). There are other statutory provisions which recognise the autonomy of a child of 16 or 17. But none of these deal with the position of a child, of whatever age, who lacks the competence or capacity (if there is a difference) to make the decision for herself. Does this mean that her parents retain the right to do so at common law? And does it mean that other people or bodies with parental responsibility, including a local authority having the child in their care, also have that right?

On the other hand, children too have human rights, not only under the UNCRC and UNCRPD, but also under the European Convention. These must include the article 5 right not to be deprived of liberty, save in the circumstances specified in article 5.1, and with the safeguards required, both by the requirement of legality in article 5.1 and the procedural requirements of article 5.4. Article 5.1(e) provides for the ‘lawful detention of person of unsound mind’. But this is only lawful if a ‘true mental disorder’, ‘of a kind or degree warranting compulsory confinement’ has been established on the basis of ‘objective medical expertise’ (*Winterwerp v the Netherlands* (1979-80) 2 EHRR 387, para 39). In *HL v United Kingdom* (2005) 40 EHRR 32, the ‘Bournewood case’, the European Court of Human Rights held that the informal admission of a patient who lacked the capacity to decide for himself, on the basis of the common law doctrine of necessity, was not ‘lawful’ for this purpose. There were none of the safeguards which might be expected to protect the patient against arbitrary decisions – defined criteria, processes, time limits and so on. There was also a breach of article 5.4, which requires that ‘everyone deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if his detention is not lawful’. So if children have the same rights as anyone else, then they too should not be deprived of their liberty without any of the safeguards which might render their detention lawful.

Ah yes, says the other side. But in *Storck v Germany* (2006) 43 EHRR 6, the Strasbourg court had said that there were three components of a deprivation of liberty for the purpose of article 5. The first is confinement; the third is attributability to the state; neither is any longer in issue in this case. But the third is lack of consent. So, it is said, the parents (or indeed anyone with parental responsibility) can supply that consent for a child of any age who lacks the capacity to decide for herself. In *Nielsen v Denmark* (1989) 11 EHRR 175, the Strasbourg court held, by a majority, that confining a 12-year-old boy, who was not suffering from a mental illness, in a locked psychiatric ward for several months was within the scope of his mother’s parental authority and therefore did

not violate his rights under article 5. The majority were influenced by the fact that conditions in the psychiatric ward were no different from conditions in any other hospital ward to which he might have been admitted for treatment for physical illness or injury. There was a powerful minority dissent.

In the case of D, the government favours the view that the parents can give their consent, although it also argues that in doing so, they must be acting in the best interests of their child. But the law does not insist that parental responsibility always be exercised in the best interests of the child. How could it? And if it did, how could this be enforced? And how could a placement safely act upon the parents' consent without some external reassurance that the parents were indeed acting in their child's best interests?

I notice that these are questions which also trouble the Northern Ireland Commissioner for Children and Young Persons. In last year's *Statement on Children's Rights in Northern Ireland*, she expressed concern on two fronts. First, although the Mental Capacity Act (Northern Ireland) 2016, when brought into force, will apply to 16 and 17-year-olds, its protections can be circumvented if the parents consent - except, she says, in the case of deprivation of liberty (which may perhaps be a reference to the decision of the English Court of Appeal in *RK v BCC* [2011] EWCA Civ 1305). Second, the 2016 Act does not apply to children under 16, who will still be covered by the amended Mental Health (Northern Ireland) Order, which has several defects. But in any event, if the common law still allows parents and others with parental responsibility to consent to the detention and treatment of children who lack the capacity to decide for themselves, there will usually be no occasion to invoke the compulsory procedures and the safeguards they entail.

I cannot predict what our answer will be. But the case is certainly a test of whether or not our law really believes that mentally disabled children have the same rights as anyone else. Children in

Northern Ireland are fortunate that they have the Children's Law Centre which is dedicated to championing their rights both individually and collectively. I salute you.