

Disabled children, the Children Act and Human Rights

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Disabled children and human rights

Disabled children, like all children, have important rights under the UN Convention on the Rights of the Child. These rights can be summarised as follows:

- Disabled children have the human right to be included in their local community and to do the kinds of things that non-disabled children do. They have the right to support to help them do this.
- Disabled children have the human right to take part in play and leisure activities and to freely express themselves in cultural and artistic ways. They have the right to equal access to cultural, artistic, recreational and leisure activities.
- Disabled children have the human right to live with their parents unless this is not in their best interests. They have the right to services to make it possible for their families to look after them.
- Disabled children have the human right to express their views and for these to be taken into account. They also have the right to freedom of expression.
- Disabled children who spend time away from home because they need care or treatment have the human right to a review of the placement at regular intervals
- Disabled children who do not live with their families, temporarily or permanently, have the human right to special protection and assistance

which takes account of their ethnic, religious, cultural and linguistic background.

Rights and entitlements

Before looking at whether the Children Act has been effective in enabling disabled children to access their human rights I want to get clear the difference between, and the relationship between, human rights, civil rights and entitlements. I think it is important to do this if we are to be clear what action is required in order for disabled children to access their human rights. I want to do this by exploring three different statements.

'Disabled children have the right to participate in the same kind of leisure activities as their non-disabled peers.'

This is a *human right*: it is a right that disabled children have by virtue of the fact that they are *human beings*, that they are the *same* as any other child. It is a *universal* right and is in fact enshrined in the United Nations Convention on the Rights of the Child, Article 23, which says: 'States Parties recognise 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.'

'Disabled children have the right to enter their local cinema.'

This is a *civil right*: it is a right that disabled children have by virtue of the fact that they are *citizens*, that, within this particular society, they have the right to be treated the same as other citizens. Again, it is based on disabled children being the *same* as nondisabled children – they are citizens of their country in the same way that nondisabled children are. It is in fact enshrined within the Disability Discrimination Act, Section 19 (1), which states 'It is unlawful for a provider of services to discriminate against a disabled person -

- (a) in refusing to provide, or deliberately not providing, to the disabled person any service which he provides, or is prepared to provide, to members of the public;....'

Disabled children need this kind of *civil right* (i.e. protection as citizens under the laws of the society in which they live) if they are to have access to their universal human rights.

'Disabled children have the right to assistance with travelling to and from services which enable them to fully participate in the life of their community.'

This is an *entitlement* to a particular form of assistance that disabled children require if they are to have access to both their human and their civil rights. It is based on the recognition of *difference*, the recognition of *additional requirements* that some children need if they are to access their right to be treated the same as all children. This particular entitlement is referred to in both the Children Act and the 1970 Chronically Sick and Disabled Persons Act.

The Children Act (Schedule 2, Part 1, Paragraph 6) says:

'Every local authority shall provide services designed

(b) to give [disabled children] the opportunity to lead lives which are as normal as possible.'

Paragraph 8.

'Every local authority shall make such provision as they consider appropriate for the following services to be available with respect to children in need while they are living with their families -

....

d. facilities for, or assistance with, travelling to and from home for the purposes of taking advantage of any other service provided under this Act or any similar service....'

The recognition of *difference* therefore can be an important way of getting access to the *same* things as everybody else. The trouble is that historically and still today, when disabled children's difference is recognised it is all too often in a context of being separated from their nondisabled peers and being denied both their civil and their human rights.

The Children Act and human rights

The Children Act 1989 was the British government's attempt to implement the UN Convention on the Rights of the Child but, as far as disabled children are concerned, it has, both in the way the legislation was drafted and in terms of how it has been implemented in practice, been a series of missed opportunities.

If we start by looking at how Article 23 is implemented. This recognises disabled children's right to:

enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.

Disabled children also have the human right to assistance provided 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.

This is about recognising disabled children as full human beings - something which continues to be important to stress as every day disabled people have experiences where they are treated as less than fully human.

The Children Act echoes the rights contained in Article 23 by requiring local authorities to provide services designed

- (a) to minimise the effect on disabled children within their area of their disabilities; and
- (b) to give such children the opportunity to lead lives which are as normal as possible.

(Children Act, 1989, Schedule 2, Part 1, Paragraph 6)

The problem is that the wording in the Children Act reflects a medical model of disability, and this is incompatible with a philosophy of social

inclusion, a philosophy of including disabled children as full members of our society and our communities.

The social model approach has been succinctly summed up by young disabled people themselves:

For many years doctors, social workers and other people have told disabled people that they are disabled because of 'what is wrong with them' - their legs don't work, they can't see or hear or they have difficulty learning things, just to give a few examples. This is known as the medical model of disability. It says that it is the person's 'individual problem' that they are a disabled person.

What we say is that yes, we do have bits of us that don't work very well, this we call our impairment: for example a person who cannot hear very well has a hearing impairment. What we say is that it is not this impairment which makes us a disabled person, it is society which makes us disabled. Society does not let us join in properly - information is not in accessible formats, there are steps into buildings, people's attitudes towards us are negative. So society puts barriers before us which stop us from taking part in society properly - it disables us. This is known as the social model of disability.'

(Greater Manchester Coalition of Disabled People, Young Disabled People's Group, 1996)

The key is in the use of the word 'disabilities'. The Children Act uses this word to mean 'impairment' so the requirement is to 'minimise the effect' of children's impairments. This doesn't get us very far in terms of tackling children's experiences of social exclusion. Instead, services should be 'minimising the effect' of disabling barriers if children with physical and/or sensory impairments, and/or learning difficulties are to be fully included with their local communities.

It has been particularly difficult for social services organisations to break away from impairment-centred approaches in the context of the need to ration scarce resources and of many resources already being tied up in expensive specialist services which separate children from their non-disabled peers and local communities.

For example, eligibility criteria focus on impairment rather than children's needs: The definition with the Children Act of 'disabled child' focuses on impairment and encourages social services departments to use definitions of 'profound and severe impairment' as a way of gatekeeping access to services. What happens in practice is that social workers have to determine whether the child falls into the category of 'profound and severe' impairment and then they are slotted into specialist and segregated services

There are many missed opportunities in that assessments, care plans and reviews do not identify the disabling barriers experienced by children.

Research commissioned by the Who Cares Trust (Morris, 1998b) identified many situations where families were experiencing a number of problems, where parents were finding it difficult to cope, but - because there was a disabled child in the family - the problem was identified as one of coping with the disabled child and the solution was to offer the parent respite from looking after the child.

Another example of missed opportunity is that Looking After Children documentation does not prompt social workers to identify disabling barriers.

Paradoxically, an approach which focusses on impairment, rather than disabling barriers, also often fails to identify needs arising from impairment. This is a disabling barrier in itself (and a reminder that the

social model approach does not deny or ignore health needs or needs relating to impairment). A common example is where a child's needs relating to communication impairment are not taken seriously.

Disabled children have the human right to take part in play and leisure activities and to freely express themselves in cultural and artistic ways. They have the right to equal access to cultural, artistic, recreational and leisure activities. This is contained in Article 31 of the UN Convention on the Rights of the Child which recognises:

the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.

It also requires governments to:

respect and promote the right of the child to participate fully in cultural and artistic life and ... to encourage the provision of appropriate and *equal opportunities* for cultural, artistic, recreational and leisure activity.

However, referrals and assessments do not focus on disabled children's rights to leisure, recreational and play activities nor to their entitlements under the Children Act, and under the 1970 Chronically Sick and Disabled Person's Act to support to access these things.

Resources remain tied up in segregated services rather than being used to help disabled children gain equal access to cultural, artistic, recreational and leisure activities.

There are a few local initiatives which seek to give disabled children access to their rights to equal access with their nondisabled peers but they are few and far between, often under-resourced and there is little recognition by social services authorities that such initiatives should be supported as part of their implementation of the Children Act.

Needs-led assessments would focus on children's rights to play, to equal access to leisure and cultural activities, etc. but all too often there is a failure to carry out assessments based on needs. Instead the focus is often on whether the child fits the service's eligibility criteria and this inevitably results in a denial of human rights. This is reflected in disabled children's experiences of being forced to fit in with services rather than services being tailored to meet their needs. As one young person said 'I get told you've got to be versatile. What they mean is you've got to fit in with what we've got available for you.'

Perhaps the most important thing to stress is that disabled children have the human right to express their views and for these to be taken into account. They also have the right to freedom of expression.

Article 12 of the UN Convention on the Rights of the Child recognises the right of the child

who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'.

It goes on to say:

the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.'

Article 13 states that:

The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

The Children Act Guidance and Regulations promote these rights for disabled children:

Learning to make well-informed choices and making some mistakes should be part of every child's experience. Children and young people should be given the chance to exercise choice and their views should be taken seriously if they are unhappy about the arrangements made for them. Plans should be explained, discussed and if necessary, reassessed in the light of the child's views.....

If the child has complex needs or communication difficulties, arrangements must be made to establish his views....Even children with severe learning disabilities or very limited expressive language can communicate preferences if they are asked in the right way by people who understand their needs and have the relevant skills to listen to them. No assumption should be made about 'categories' of children with disabilities who cannot share in decision-making or

give consent to or refuse examination, assessment or treatment.

If a child is placed in a form of care outside their home (whether it is short-term 'respite' care or longer-term) the social services department must 'ascertain [their] wishes and feelings' and take these into account when making decisions (Children Act, Sections 20 (6), 22 (4) and (5)).

Disabled children and young people are often denied their human right to communicate their views

Research on the experiences of young disabled people who had spent most of their childhood living away from home found that many of them:

- did not have access to a communication system which suited their needs
- did not have routine access to people who understood the ways they communicated
- did not have access to independent facilitators.

(Morris, 1998a)

One of the most disabling attitudes faced by children with physical or sensory impairments and particularly by children with significant learning difficulties, is the assumption that they do not have a view to express or a way of expressing it. Our society operates as if communication only takes place through written or spoken language. Thus people who use other methods of communication - sign language, body language, the 'language of the eyes', the language of sounds - find that the skills of observation are very underdeveloped and undervalued. Their communication systems can therefore remain unrecognised.

Disabled children and young people are rarely consulted when assessments and decisions are made about short-term and long-term placements. The Department of Health's inspection of four

local authorities, carried out in 1993 found that there was little evidence of disabled children's 'wishes and feelings' being 'ascertained' (Social Services Inspectorate, 1994, p.4). The Department's second inspection, carried out in 1997, also found a need for better communication with disabled children (Social Services Inspectorate, 1998) and The Who Cares? Trust research suggests that there has not been much improvement in furthering this particular entitlement (Morris, 1998b). This research looked at the decision-making processes of two Resources Panels, one in a City Council and one in a County Council. In the case of the City Council:

In only 12 out of a total of 66 cases presented to the Panel had the social worker attempted to find out the child's views. In at least five cases, the social worker had not even seen the child. Typically, the section of the form headed 'Child's view' was left blank or the social worker made comments such as, 'She is unable to verbally communicate and therefore her view is not available'; 'It is not possible to know what his views are owing to his level of disability.'

In the case of the County Council:

Of 24 cases submitted, in 11 instances the social worker wrote 'Not applicable' in the section headed 'Child's perception of need' and in another nine cases the section was left blank.

One important message is that the 'children first' principle is not adequate to understand how disabled children can be included in their local communities. Equal access is not made possible solely by equal treatment. For example, a failure to pay attention to the particular communication needs that disabled children have has meant a denial of their right to be consulted in decisions about what happens to them.

Which brings us back to the relationship between rights and entitlements. Unless disabled children's specific requirements are recognised in ways which enable them to be included, in ways which enable them to have equal access to the things their nondisabled peers take for granted, then they will continue to be denied access to their human rights. The implementation of the Children Act should therefore be about identifying the disabling barriers that children experience, and about tackling these disabling barriers.

Conclusion

Every day, in every part of Britain, disabled children's human rights are being contravened - unknowingly and carelessly, as well as deliberately. All actions of statutory and voluntary organisations in this field must be measured against the extent to which they promote disabled children's human rights. Flawed though the Children Act is, it could yet be used more constructively. Disabled children are entitled to specific help to tackle disabling barriers and a needs-led, rather than a service-led, approach will enable them to make choices in their lives, thus protecting them from a denial of their human rights.

Human rights are about what we all have in common, by virtue of the fact that we are human beings. Throughout the world today, and throughout history, there are horrifying examples of what happens when one group of people see another group as less than human. Children who have physical, sensory and/or intellectual impairments have also been treated as less than human, resulting in segregation, discrimination and sometimes a failure to recognise their right to life. Promoting the 'welfare' of disabled children (and indeed all children) should be about promoting their human rights.

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