Disability and adoption* How unexamined attitudes discriminate against disabled people as parents

For many years Michelle Wates has been involved in developing peer support and a campaigning network of disabled parents in the UK. She considers that, while disabled children and adoption have been the focus of some debate, the issue of adoption has received far too little attention in relation to disabled adults. This article seeks to redress the balance by looking first at how children with disabled parents are over-represented in the looked after system. The author goes on to discuss the ways in which disabled people are overlooked as potential adoptive parents. In conclusion she outlines the implications for practice regarding both these related areas of concern.

Introduction

Discussions about the relationship between disability and adoption have tended to focus on the issue of finding suitable adoptive parents for disabled children and have largely overlooked the issues in relation to disabled adults in a parenting role. Furthermore, proposed government legislation aimed at ‘simplifying’ the adoption process (the Adoption and Children Bill) may have a discriminatory impact upon certain groups of parents, including parents who are ill or who have physical or sensory impairments, learning difficulties or mental health problems. Many of these parents have limited access to advocacy services.

The intention of this article is to inform emerging debate and research by highlighting two related areas of concern:

1. Are disabled parents losing children unfairly to the looked after system and to adoption?

Limited access to support

It is known that good support makes a crucial difference to outcomes for families (Booth and Booth, 1998). However, disabled parents’ access to specialist social care, mainstream parenting services, informal networks of support, as well as to specialist information, resources and equipment, are all limited by the inaccessibility of the built environment, information systems and support structures. Where more might be needed because of disabled adults’ particular requirements, the reality is that less support is available than to non-disabled parents.

Mainstream parent support has tended to overlook disabled parents, perhaps assuming that their needs were already being met by specialist services. How-

2. Disabled people are under-represented, both among people who apply to become adoptive parents and among those who get through the selection and allocation processes.

The first part of the article considers the issue of support to disabled adults in their parenting role. This shows how children may enter the looked after system without their parents’ specialist support needs ever being assessed or even addressed. Also, once children are looked after their disabled parents are often at a disadvantage when seeking to influence plans or retain contact. The second part examines the unrecognised potential of disabled people as prospective adoptive/foster parents.

Key words: disability, adoption, disabled parents, discrimination

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In the UK, disability now normally includes physical and learning impairments, chronic illness, learning disabilities, mental health problems and, in some circumstances, addictions.

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ever, *A Jigsaw of Services* (Social Services Inspectorate, 2000), the report of an inspection carried out in England by the Social Services Inspectorate (SSI), shows that parenting tasks and roles are seldom included in the eligibility criteria for adults receiving health and social services. Parenting responsibilities are not considered when assessing levels for Severe Disability Allowance or the Disability Living Allowance, and childcare tasks are specifically excluded when considering eligibility for the Independent Living Fund.

Since support is not routinely available to disabled parents in their own right, a service may only be triggered when a child is designated as being ‘in need’ or ‘at risk’, in which case the service will be provided in line with children’s legislation, using the *Framework for the Assessment of Children in Need* (see Ward and Rose, 2002).

It might be argued that the reason for focusing on a child as being ‘in need’ within the terms of the Children Act 1989 is to avoid a situation where child protection procedures come into play. However, the fact that parental capacity is brought into question without first mobilising appropriate specialist adult services (as part of community care provision) to support disabled adults in their parenting role, is not in keeping with central government directives to encourage services to promote independence and prevent problems from arising.

The effect has been to institutionalise poor levels of support and to interpret problems that arise within families as evidence of parental incapacity. Many parents are wary of stigmatising labels being applied to their families. They are fearful of this leading to procedures that will undermine their parenting role and have the effect of separating them from their children, whether in the short or long term.

*Inappropriate use of child protection measures*

SSI inspectors found that child protection investigations were not always ‘used appropriately’ (Social Services Inspectorate, 2000, App G). Although parents with mental health difficulties were not included in the SSI inspection, the findings of a separate study commissioned by the National Institute for Social Work reflected similar concerns: ‘Collaborative working across organisations is often about child protection issues, at the expense of family welfare considerations’ (Kearney *et al.*, 2000, p 49).

There is no evidence to show that neglect or deliberate abuse occurs any more often among disabled parents than among non-disabled parents. What research does reveal, however, is the high levels of parental mental illness and/or learning disability in parents of children who become involved in child protection procedures (Department of Health, 1995). *A Jigsaw of Services* (Social Services Inspectorate, 2000) shows that, at least in the case of parents with learning difficulties, it is questionable whether this high prevalence is justified by what happens in families. Rather they suggest that it is brought about in part by the way in which services respond, by inappropriate thresholds for receiving community care services and by reluctance in some areas to recognise disabled adults’ additional needs as parents (paras 5.6, 5.12).

In the light of the above it is perhaps no surprise to find that disabled parents figure highly in statistics on children removed from home. According to the Department of Health’s own figures for 1999 and 2000, ‘parental health’ was the third commonest reason given for a child entering the looked after system. It was almost certain that the second commonest reason, ‘parent needs relief’, also included disabled parents (Department of Health Public Statistics, 2000).

*Support for birth parents falls off the agenda*

To do the work required in supporting families properly takes time and can be complex. Pressure on professionals to minimise parental involvement and consultation in the interests of a less complicated, cheaper and speedier process threatens the interests of both children and their families.

At the point when serious family difficulties arise, issues such as confidentiality, consultation, service co-ordination...
and continuity of relationship with key workers become particularly crucial concerns. However, an analysis of social service departments’ written policies/protocols in relation to providing services to disabled parents (Wates, 2002) shows that it is precisely at this point that such issues are likely to become secondary considerations and may fall off the agenda altogether.

Where child protection is a concern, normal procedures in relation to confidentiality, consultation and the routine involvement of adult services are not necessarily seen as applying. A number of protocols appear to suggest that standard procedures may be summarily waived in child protection situations. This must be a cause for concern when set alongside the findings of the SSI inspectors, cited above, that child protection investigations were by no means always used appropriately.

The importance of advocacy

Once children have entered the ‘looked after’ system there may be increasing focus in practice upon further separating them from their parents, rather than working to reunite the family. Access to advocacy services is not routinely provided and many parents are unsuccessful in obtaining this kind of support or may even be unaware of its existence. For example, an application had been made for the adoption of the children of a woman hospitalised following mental health problems. In spite of the fact that she had expressed her opposition to the adoption of her children, nobody had given her the information that there was an advocate assigned to the hospital, until she learned it from her mother who had consulted a local disabled people’s organisation. Following work with an advocate, the adoption order was not pursued and the children went into foster care with the continued involvement of the mother.

Many have expressed disquiet that moves to speed up the adoption process in the supposed interests of the child will create additional barriers for parents and children who have become separated, often against their will. These include

Disabled Parents Network, organisations related to foster care, family rights lawyers, advocacy and support organisations for people with learning difficulties and mental health problems.

Crowley House Project, based in Bristol, was set up because parents with learning difficulties reported coming under pressure to give up their children for adoption against their wishes. A mother contesting the adoption of her two children was told that the boy, who had behaviour difficulties, would be allowed to return to the mother but it was said in court that his sister was ‘perfectly adoptable’. With the aid of the advocacy project, the mother eventually got both children back, although the process took three years.

Discrimination in the courts

Social services personnel might argue that the rigorous legal process followed in making decisions in relation to the adoption of children in the looked after system in itself safeguards both parents and children’s rights. The fact is that in England the judiciary are not obliged to have training in anti-discriminatory practice.

Where a case involves a disabled parent, the presence of impairment will often be cited as a reason why a child ‘will have a better life chance’ with the non-disabled parent or even in the care of a local authority. In the case of parents with learning difficulties such challenges are particularly likely to go unquestioned.

Australian researchers based at the University of Sydney have carried out the first major research study to test the hitherto largely anecdotal evidence that disabled parents and their children were treated unfairly. The writers concluded:

Children have been removed even when the evidence of neglect presented has been refuted and parental adequacy acknowledged by the court. In some cases, children have been removed despite evidence demonstrating that the parent was making progress toward overcoming the difficulties that led to child removal. (McConnell et al, 2000, p 3)
It has been suggested that much the same happens in Britain and researchers Tim and Wendy Booth at Sheffield University are currently undertaking a similar study in the UK.

Adoption – the impact of the ‘new approach’

Alison Richards of the Family Rights Group, a voluntary sector organisation that promotes partnership between families and childcare agencies, echoes the above concerns:

The Adoption and Children Bill, with its emphasis on speed and ‘simplification’, does not sit comfortably with the Children Act’s requirement that children should remain wherever possible within their families. (Personal communication)

An increased emphasis on the notion of adoption as representing permanence without any counterbalancing attention to issues of support within the family gives rise to human rights considerations.

The proposed legislation places no obligation on either adoption agencies or prospective adoptive parents to consider the role that birth parents might play in their children’s long-term future. Nor is there any provision for post-adoption support for birth parents. To quote Alison Richards again:

What is in prospect is a very fast-moving process, in which birth parents get left behind at first base with no prospect of catching up. (Personal communication)

The key human rights principle here is that of proportionality. In other words the right to family life may be qualified, but where it is restricted the intervention must be proportional to the needs identified and goals agreed/desired. Adoption is one possibility, but usually only where prevention or protection with rehabilitation have not resulted in adequate care for children. There may be some circumstances where accommodation rather than care proceedings has been used to safeguard and promote the welfare of the child, but proportionality would mean being able to demonstrate that adoption was the only long-term option once other avenues had been explored (Preston-Shoot et al, 2001).

In the past, fostering often provided a positive short-term support strategy for parents under pressure, with the goal of reuniting families wherever possible. Even prior to the proposed changes, many disabled parents were reluctant to approach social services voluntarily to seek help in times of difficulty for fear of finding that children were removed from home. Fostering support organisations are concerned that parents will become increasingly wary of respite options, fearing that adoption proceedings might start ‘through the back door’ while children are temporarily accommodated.

The danger is that the commitment to supporting families will come into conflict with the drive to fast-forward adoption. This fear appears to be borne out by the observations of family rights and support workers on the ground. It raises the question of whether it is fair that social services departments should have responsibility for both these functions or whether it might be more sensible to split the functions as is the case in, for example, New Zealand and France.

It is enshrined in law that the welfare of children must be considered paramount. It is widely understood and promoted by government and within the child support sector that the needs of children are most appropriately met wherever possible within the context of the family, and that the best way to ensure that this can happen, is by providing timely and appropriate support to parents. This should apply to disabled parents the same as to any others.

The second half of this article shifts attention from disabled parents who risk losing their children to disabled parents as a resource for looking after other people’s children.

2. Disabled people as prospective adoptive/foster parents

An untapped resource

For some time now it has been recognised that disabled people may make particularly appropriate adoptive parents for
disabled children. There is also increasing recognition that the experiences and perspective of disabled people equip them well to parent children who, whether or not they are disabled, nonetheless have a sense of themselves as different (Caine, 1990).

Disabled parents themselves have pointed out that disabled people make fine potential adoptive parents per se, and that this would be the case whatever the situation of the child. We know that some of the skills acquired in the course of our experience as disabled people – adaptability, resourcefulness, patience – actually make us particularly well suited to the task of parenting! In the words of Argent and Kerrane (1997, p 28), 'A proven ability to overcome problems is a more positive indicator than a trouble-free life.'

Disabled parents have qualities and offer experiences that children value. Examples are the tendency to move at a slower pace and in some cases at a lower level, the willingness to spend more time sitting down and rather less time rushing about, and a certain flexibility around the number of different approaches that can be taken towards reaching a goal.

In addition the children of disabled parents and their friends receive something of great value in a society that has so many misconceptions and fears about disabled people. There is much to be gained from the quietly educative experience of living alongside disability in the context of positive, familiar relationships, rather than seeing it as something remote and threatening.

In spite of this, organisations, such as Disabled Parents Network, Disability, Pregnancy & Parenthood International and British Association for Adoption and Fostering (BAAF), are concerned that disabled people are in reality less likely to get through the adoption selection process (in relation to both disabled and non-disabled children) than their non-disabled counterparts. In addition, if they do get through, they seem to be less likely to be allocated children to adopt. There is clearly a need to investigate and establish whether and to what extent this is the case and, if so, how it is happening.

The resource issues
Disabled adoptive parents and prospective adoptive parents are faced with the same difficulties in getting their parenting support needs met as has been described above in relation to other disabled parents described. In their case, too, this is more likely to be put down to the limitations and incapacities of disabled individuals, than it is to be recognised as a failure of support systems and services. It may be that the existence of support needs is regarded as a reason in itself for rejecting an application to adopt or else is seen as a barrier to allocating children to parents who have been approved.

The presence of a physical or cognitive impairment in an applicant will rarely be cited as the reason for turning people down. Professional reticence on this issue may in fact be part of the problem. If concerns are identified up front, then they can be discussed and any resource issues addressed. When, however, they remain on the level of unvoiced assumptions and fears on the part of professionals they easily become a discriminatory barrier.

The issue is related to the problem identified in the first part of this article – that of disabled birth parents whose support needs are seen as evidence of parental inadequacy rather than as an indication of the need to provide appropriate community care services.

Some of those who have got through the selection process report that they themselves had to educate and reassure their assessors as part of the process, teaching them to recognise the social, environmental and structural context of disability rather than seeing it purely in terms of the specifics of an individual’s medical condition. Lessons might be learnt from positive policies in other parts of northern Europe where enhanced allowances are paid to adults who foster or adopt disabled children. Only in this way can a significant potential parenting resource be tapped.

Need for research
In order to establish whether disabled applicants are being placed at a disadvantage in the adoption selection and allocation process it is necessary to
establish the numbers of disabled people applying to adopt and/or foster children (both disabled and non-disabled children), and how successful they are in getting through the selection procedures compared to their non-disabled peers. Research should compare success/failure rates at all stages of the adoption process including post adoption.

It would be useful to know more about disabled adults’ reasons for wanting to adopt or foster, and whether disabled applicants are deterred by resource or other considerations from applying in the first place. Such research should also look at perceptions in relation to both the selection process and the experience of adoption. This would involve disabled adults, prospective parents, social workers, adoption panel members and, where appropriate, children themselves. (A study proposal is currently being prepared by BAAF, Disabled Parents Network and the Centre for Disability Studies at Leeds University.)

Cultural issues
There is a need for a debate similar to that which has taken place over many years around race and adoption. A key issue running through both debates is the effects of institutionalised discrimination on parenting. It may be that there is even less societal understanding of how this operates in the lives of disabled people than in the lives of people from minority ethnic backgrounds. Prospective adoptive/foster parents who are both black and disabled face a double discrimination.

On the positive side, arguments are employed similar to those used in relation to the value of adoptive parents from ethnic minorities. Points are put forward about shared experience, positive role models, common culture and the positive contribution of difference and resilience to affirm that disabled people may make good parents for disabled or other hard-to-place children.

However, some disabled prospective parents question why it is that they are less likely to be considered as potential parents for non-disabled children. Suggested reasons include the danger that children may be teased or bullied on account of having disabled parents, the effect on a child’s self-image and concerns about the practicalities of child care. Another consideration may be hinted at, namely the question as to whether adoptive children with disabled parents will be obliged to take on inappropriate caring tasks.

In so far as any of these are valid objections they would, of course, apply equally or perhaps rather more to disabled and other ‘hard-to-place’ children. It may be that other assumptions are operating that are less likely to be stated, either because they would clearly be discriminatory or because they are held at an unconscious and therefore unexpressed level. One belief is that it would be unfair on ‘normal’ children to land them with disabled parents. The view may be taken that, since disabled adults and disabled children are ‘hard to place’, it makes sense to put them together.

Many disabled people do in fact specify that they would prefer to adopt a disabled child and give positive reasons for their choice (Wates and Jade, 1999). While this is construed by adoption agencies as a valuable cultural identification, it is essential that the resource implications are also taken on board, since the requirements of a disabled parent of a disabled child may be greater than the sum of individual needs.

Implications
1. Are disabled parents losing children unfairly to the looked after system and to adoption?

- The issue of support for parents should always remain on the agenda so that appropriate adult specialist teams and/or advocates be involved throughout.
- The availability of advocacy services is particularly crucial where children are removed from home or where there is any potential erosion of family rights.
- Social services departments should consider the role of developing cross-over posts or even a distinct division to serve the needs of disabled adults in their parenting role.
Local authorities should be required to demonstrate what they are doing to support disabled adults in their parenting role in order to help keep families together and/or reunite families where children are being looked after.

Agencies and divisions concerned with parents and children should follow agreed and compatible procedures.

2. Disabled people as prospective adoptive/foster parents

Disabled adults’ support requirements in relation to their personal care and/or in relation to parenting tasks should not be a barrier to them becoming adoptive or foster parents.

Support requirements of disabled adults who have been approved as potential adoptive or foster parents should be addressed in good time using appropriate specialist support.

Steps must be taken to make these resources available from the outset and keep them under review, as parenting tasks change with the child’s developmental needs.

3. Good practice in respect of any placement with disabled adults who have parenting responsibilities

The following measures should be explicit in professional protocols relating to adoption:

- The paramountcy of children’s welfare children’s interests should mean that wherever a disabled adult has parenting responsibilities for dependent children, including adopted children, services that will expedite and support the parenting role should be prioritised.

- There should be joint planning and delivery of training within and between relevant agencies with input from disabled parents themselves.

I visited an interactive exhibit in a museum with a fellow disabled mother and her six-year-old adopted daughter who has cerebral palsy. The information board next to the exhibit explained that the idea was to crawl through the electronically activated tunnel without touching the sides, making as little noise as possible. My friend did not pass these instructions on to her daughter but at once turned the whole thing around. ‘OK. Let’s see just how much lovely noise you make as you go through.’

Her years of experience as a disabled person have taught her to value her daughter’s own reality and not one based upon someone else’s experience. Her years as a disabled person have also shown her the value of being able to make a noise, whether the world invites us to or not.

References
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McConnell D, Llwelwyn G and Ferronato L, Parents with a Disability and the New South Wales Children’s Court, Sydney, NSW: University of Sydney, 2000
Editor needed

BAAF is looking for an editor to compile and co-ordinate an updated edition of A Bibliography of Family Placement Literature.

Last published in 1994, this popular guide to publications on children, parents and carers has proved an invaluable and handy reference for social workers and managers, teachers, researchers, doctors, lawyers, journalists, students and all those seeking information in the complex field of family placement, fostering and adoption. Far-reaching developments over the past decade – most recently the new Adoption and Children Bill for England and Wales and a major policy review in Scotland – have generated a wealth of new literature, including the rapid expansion of material available on line. An up-to-date annotated bibliography of such resources is badly needed.

The editor would need to be familiar with the wide range of issues surrounding the placement of children separated from their birth families, and have some experience of research, both in libraries and on line. A fee would be payable and we would expect you to commence work as soon as possible. If you are interested or have suggestions for an editor, please contact Shaila Shah at BAAF Head Office: Tel 020 7593 2071 or email shaila.shah@baaf.org.uk