Disability: Still taboo in family placement?

This article is based on the second annual BAAF lecture, delivered by Jennifer Cousins to the organisation’s AGM on 18 November 2008. The article explores the place of disabled children in the context of adoption and foster care. The starting point for this exploration is the belief that when professionals talk about children, the picture is one of a generic, not-disabled child; that disabled children have an untouchable status which profoundly affects their life chances; that they are at the margins of our consciousness; and that, in some measure, disability is still taboo in family placement. The influences on these perspectives are discussed, starting with a wide-ranging sweep through different cultures and historical periods before looking at how the continued marginalisation of disabled people is affecting family-finding services for children in the UK. The principal argument is that disabled children are not a separate group, but are the responsibility of everyone engaged in working on behalf of young people. The taboo must be lifted.

The cultural context of disability

Most professions have their glamorous side: the surgeon, the human rights lawyer, the sports teacher and, in social work, the child protector. Unfortunately, recent cases remind us that child protection still grabs the headlines and also tends to grab the funding. As Olive Stevenson stated many years ago:

Child abuse sometimes seems like the cuckoo in the nest, remorselessly pushing other chicks out, voraciously consuming their share of resources. (1992, p 19)

Anything to do with disability, however, comes a long way down the resources and status hierarchy. Disability ranks alongside medicine’s geriatrics and anaesthetics, and for the same reasons: like the old and the unconscious, disabled people are readily marginalised. Anyone working with ‘them’ or arguing for resources is also sidelined. There is little which is prestigious about the world of disability. At the very best (or worst?) disability evokes pity and charity.

Even in the UK’s relatively liberal society, the marginalisation of minorities is still a live issue. If asked how many prominent people in influential public positions are disabled, most respondents would agree that the number is small. And if the criteria were to be people who are disabled, Black and female, the number would shrink even further.

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This invisibility is significant, because of the way it affects the disabled population at large. Representation is a form of respect, and also of acceptance; the more visible people are, the less prejudice they are likely to attract. (Cochrane, 2008)

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It is dispiriting to find that even where social exclusion is specifically addressed, disability fails to be highlighted. In a well-informed publication undertaken for the office of the Deputy Prime Minister in 2004, entitled Including the Socially Excluded: The impact of government policy on vulnerable families and children (Buchanan, 2007), the words ‘disabled’, ‘disability’ and ‘disabilities’ appear once each. There is no reference to ‘impairment’ or ‘special needs’. 

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Before going any further, attention should be drawn to a particular contradiction which challenges everyone involved with ‘minorities’, namely how to retain an inclusive perspective on disability while identifying difference in a helpful way. Disabled people are not a homogenous group and ‘they’ are not a separate species to be hived off into separate teams of social workers (or, for that matter, to be described in a special lecture or article devoted to disability). The issues should be part of mainstream discourse. However, disabled people (whatever their individual impairment and personal differences) do share a distinct structural relationship with a discriminatory society and may have some extra requirements in common that should be valued and recognised. As this is less likely within the mainstream, there is, it can be argued, a justifiable reason why disability should be explored as a discrete issue.

It is not the intention of this article to make everyone feel uncomfortable and guilty. Discriminatory views towards disabled people are so culturally embedded that they are unavoidable. Professionals should not feel guilty about discovering that they harbour discriminatory views, but they should do everything within their power to try to change their perspective and actions.

The English language not only enshrines discriminatory attitudes but also reinforces them so that negative views are shaped unwittingly. The word ‘invalid’ comes from ‘in-valid’, handicapped is linked to the pitiful disabled person begging with ‘cap in hand’ and there are numerous examples where the disability aspect of common phrases is taken for granted: a lame excuse, blindly obvious, a dumb idea, a mad scheme, a ‘no-brainer’, falling on deaf ears. But we should not all suddenly be silenced for fear of getting it wrong; we will probably never get it right. Sensitivities move on and what is regarded as acceptable changes over time. The Curtis Report of 1946 (which led directly to the Children Act 1948), describes a ‘mongol idiot of gross appearance’ and a ‘three-year-old hydrocephalic idiot of very unsightly type’ (Curtis Report, 1946, paragraph 40). Even the Children Act 1989 uses the term ‘dumb’ to refer to children without speech (Part III, section 17). When the BBC website Ouch! (BBC, 2003) ran a survey to find out which words disabled people found the most offensive, the top ten results were:

1. spastic (the most offensive)
2. retard
3. brave
4. special
5. cripple
6. handicapped
7. wheelchair-bound
8. mong
9. psycho
10. window-licker.

It is significant that ‘special’ was voted the fourth most offensive word. This highlights the wish of disabled people to be seen as simply part of the mainstream. Another legitimate objection is to the use of de-personalised language such as ‘the disabled’, ‘a Down’s’, ‘an epileptic’, ‘an asthmatic’.

Discriminatory attitudes are taken for granted and go largely unnoticed. Middleton (1992) has compiled a roll-call of popular literature which tells of bad, twisted people and good, beautiful people. Her ‘heroes’ are Galahad (the perfect, very able-bodied knight), Superman, an alpha-male until he puts on his glasses (when he immediately becomes an ordinary wimp), Star Wars’ Luke Skywalker who is brave and handsome, and one might add James Bond, the alpha male of them all, and so on.

Middleton’s villains are Long John Silver and Captain Hook (who both had missing limbs), the Cyclops with one central eye, the Ugly Sisters, Fagin, Dr Jekyll (as opposed to Mr Hyde), witches and hobgoblins – all with physical deformities to match their evil ways. Richard III comes off particularly badly: the more it suited the political purposes of those around him, the more
apparently deformed he became, to the point where his portraits were retouched to make him ‘hunchback’.

Even great art perpetuates the mythology of disabled people as a dark force or pitiable creatures deserving charity. John Everett Millais’s 1856 painting *The Blind Girl* (www.bmagic.org.uk/objects/1892P3) shows the young person wandering with her little sister, earning a living by playing the concertina and by begging. The note pinned to her shawl, ‘Pity the Blind’, is an appeal to passers-by to donate money. A group of disabled artists have written a commentary for the Birmingham City Art Gallery which points out that:

- This is an idealised image of visual impairment, intended to inspire pity. The blind girl appears angelic and long suffering.
- She is clearly poor – one of the ‘deserving’ poor – whom it was people’s Christian duty to help.
- She is dependent upon her young helper, as with younger siblings of disabled children today.
- The double rainbows in the distance symbolise all that she cannot see but she experiences the countryside through her other senses (she is patiently fingering the grass). That blind people have heightened senses is another stereotype.
- The image also shows the stereotypical belief that all blind people are musical.

The disabled artists conclude: ‘We feel that people often still do pity us, even if they pretend not to.’

The reason that Alison Lapper was such a sensation on the fourth plinth in London’s Trafalgar Square was because the strong, dignified image of a profoundly disabled woman (naked and pregnant) was a rare occurrence. Lapper herself said of Marc Quinn’s sculpture:

*I regard it as a modern tribute to femininity, disability and motherhood . . . The sculpture makes the ultimate statement about disability – that it can be as beautiful and valid a form of being as any other.* (Lewis, 2005)

Attitudes towards disability are deeply embedded social phenomena that vary across place and time, and mainstream Western views may be regarded as unusual in other societies. Oliver analyses a range of perspectives regarding disabled people:

. . . in some societies, someone with polio may be seen as the victim of witchcraft, and someone with epilepsy as possessed by God or the devil . . . Disability is not always defined as a personal tragedy with negative consequences; it may be seen as a sign of being chosen, as being possessed by a god, and . . . the person may have their status enhanced. (1990, pp 22–23)

Other societies, at other times, rely not on beliefs or magic to explain the world but on science and rationalism. In these cultures it is more likely that medical explanations will be prominent, with the emphasis on seeking cures to ameliorate the impact of an essentially negative condition. For example, the Peto Institute for Conductive Education in Budapest teaches children with motor disorders to improve their capacity to walk. This is a lengthy, intensive and challenging process. Proponents feel the gains massively outweigh the discomfort and other sacrifices, but opponents ask ‘At what cost?’, fearing that the emphasis on ‘putting things right’ reinforces the view that intrinsically the children are second best – a disappointment and a burden to their parents.

The social model of disability counters this medical perspective:

. . . some of the greatest restrictions and limitations experienced by disabled children and adults are undoubtedly created by the way that society is organised to exclude them, by other people’s damaging attitudes, by limited and unequal opportunities and by
inadequate service provision. (Read et al, 2006, p 32)

It is therefore not simply the impairment itself which can cause difficulties. If every child learned British Sign Language at school instead of French, deaf people would have to confront fewer barriers to communication: they would be en-abled, not dis-abled. This confirms ‘disability’ as a social construct.

Attitudes to disability have also varied not just between modern cultures but across millennia. To go back to prehistory: in a hunter-gatherer, nomadic society where life was ‘nasty, brutish and short’, to be disabled probably caused life-threatening problems for the individual and for the tribe. People with restricted mobility would have found it hard to escape from a sabre-toothed tiger or catch their reindeer supper; those with learning difficulties might not have been able to remember or learn the most effective hunting methods. Disabled people would have been a burden to the community.

With the transition from hunter-gatherer tribes to rooted agricultural settlements, things may have been different. Gentle gardening or milking a goat are manageable activities for many people with a wide range of abilities and disabilities. In this kind of economy surely the attitude to impairment would have been more inclusive?

In more modern times, the discrimination ubiquitous in the capitalist West may be based on the negative view of people who are seen as economically unproductive. Before the Industrial Revolution, at a time when work was largely rural or located in small-scale workshops, disabled people could make some contribution. There were fewer hazards for the vulnerable in familiar, uncongested surroundings where, even for those with learning difficulties, skills could be acquired at a slower pace through observation and repetition, and individual inabilities could be absorbed into the co-operative effort.

It is not that disabled people would have fared universally well in this apparent rural idyll (was the ‘village idiot’ ridiculed or valued or protected?), but once the Industrial Revolution got under way and production moved to cities and fast-moving work in factories, fewer disabled people would have found acceptance in the workplace and would therefore have become further marginalised. Whether post-industrial, technological societies will once again provide more opportunities for disabled people to join the workforce remains an open question.

Back in the 19th century, without the safety-net of the welfare state, these new social pressures were devastating for anyone unable to work. The Poor Laws of 1834 led to the provision of asylums to house the ‘mad’ or ‘feeble-minded’, and the building of workhouses and special schools where disabled people could be segregated according to ‘type’. These institutions were places both of benevolent refuge and social invisibility. People who were different were quite literally ‘out of sight, out of mind’, arguably a feature of some residential settings and special schools even now. The 19th-century institutions also served a more sinister purpose. The Mental Deficiency Act of 1913 renamed them ‘colonies’, the purpose of which was to separate their residents from mainstream society. There was no doubt about who was being protected:

Let us assume that we could separate all the families containing mental defectives . . . this would include a higher proportion of insane persons, epileptics, paupers, criminals, habitual slum dwellers . . . If we are to prevent the racial disaster of mental deficiency . . . we must deal with . . . the whole sub normal group. (Wood Committee, 1929)

The fear that ‘mental defectives’ (among others) might infect the wider population and cause society to degenerate became widespread and led in turn to the Eugenics movement. The ultimate aim of this group, spearheaded by Sir Francis Galton (interestingly, and...
perhaps not surprisingly, a cousin of Charles Darwin), was no less than to *breed out* problems and thereby improve the human gene pool. The Eugenicists’ advocacy of genetic counselling, laws to restrict ‘breeding’ to the intelligent and physically fit, pre-natal screening, enforced sterilisation and pre-emptive abortions were all seen as stepping stones towards the creation of a perfect race. The ancient Greeks had a similar aim, killing deaf children, and, in the case of the Spartans, throwing those with impairments into pits.

The 19th and first half of the 20th centuries therefore saw disabled people separated not only from mainstream society, but also grouped into institutions that focused upon a particular impairment. The paternalistic charities, which were expanding at the time, thus found it easier to take up the cause of separate groups of disabled people. They founded organisations such as the Royal National Institute of Blind People (1868), the Royal National Institute for Deaf People (1911), Mencap (1946 – formerly the National Society for Mentally Handicapped Children); and Scope (1952 – until 1994, the Spastics Society).

Charities also aimed to generate funds by using promotional images which played on the theme of pity: the sad little Mencap boy; the lonely, shadowy child separated from his family, and the image of a single piece of jigsaw (both Autistic Society). In the beginning, the charities’ philosophy was to do good things to the disabled and the deserving poor, relegating them to an underclass who were denied the means to manage their own lives, but were required to be eternally grateful for being rescued.

Though many charities are now inclusive in their approach, with disabled people playing a full part in the management of the organisation, the Disabled People’s Movement opposes the whole notion of charity and promotes a rights-based approach. Michael Oliver writes trenchantly:

> In many so-called less civilised societies, disabled people are at least accorded the dignity of begging on their own behalf. (1990, p 93)

The latter half of the 20th century saw the foundation of the welfare state, which arose from initiatives in post-war reconstruction and was responsible for momentous social change. At the time of its conception, national governments could, by and large, control their own economy and provide employment for men and protection for women and children. But 21st-century governments, inexorably linked to world economics and global events, can no longer do this. In the UK, rather than providing the traditional safety net for the most vulnerable, the Government now argues that the most efficient way to provide welfare is to support all people into paid work and, through early years education and programmes like Sure Start, to create what is trumpeted as ‘the workforce of the future’. Speaking in September 2008 about the new ‘Access to Work’ initiative, the Secretary of State for Work and Pensions, James Purnell, said:

> There has been a revolution in the rights, expectations and demands of disabled people, which means the attitudes of others must change. Disabled people must have the same opportunities and same right to work as all people. (2008)

As only about half of adult disabled people are in work (compared with 80% of non-disabled people), this seems a laudable objective. However, its message could be that the individual should be productive at all costs, with obvious implications for those unable to join the labour force.

We are also witnessing the dual rise of consumerism and celebrity where physical beauty has inordinately high status. People who differ are urged to aspire to become more ‘normal’ or more beautiful. There is even reported to be an alarming rise in the number of cosmetic procedures performed on
adolescents. The sheer banality of this perspective is revealed by Oliver’s description of an isolated tribe in West Africa where many of the population were born with only two toes:

_This made no difference to those with only two toes or indeed the rest of the population. Such differences would be regarded as pathological in our society, and the people so afflicted subjected to medical intervention._ (1990, p 14)

Suddenly this turns any perception of ‘normal’ on its head, but it also raises problematic moral issues for any society which seeks to perpetuate a narrow definition of normality.

Both the Abortion Act 1967 and the Human Fertilisation and Embryology Act 2008 talk of ‘screening out’ ‘abnormal’ embryos which appear to have conditions that will lead to serious disability. Bob Edwards, who led the team behind Britain’s first test-tube baby, is reported in 1999 as saying:

_Parents will soon have a moral duty to abort pregnancies when a severe disability is detected . . . We are entering a world where we have to consider the quality of our children._ (Metro, 5 July 1999)

However, another commentator, Dr Mark Hamilton of the British Fertility Society, reviewing recent developments in gene-mapping, takes the view that ‘If you can screen for anything, where do you draw the line?’ (news.bbc.co.uk/1/hi/health/7688299.stm). Any movement that endorses the creation of ‘the perfect child’ raises very complex moral issues and ultimately diminishes the value of people regarded as less than perfect, and belittles the contribution which disabled people can make.

This extensive survey of underlying socio-historical factors shows that attitudes towards disability are deep-rooted, widespread and culturally specific. They will inevitably determine the extent to which the environment is shaped to meet the needs of disabled people, whether they are included and valued or made invisible, and to what degree impairment is individualised and problematised.

Particular attention is drawn to the work of Michael Oliver, whose book, _The Politics of Disablement_ (1990), is the inspiration for many of the avenues explored here.

**Disabled children**

This review of cultural attitudes to disability now leads to a consideration of services for disabled children who need new families. It is not an auspicious start. Children have been valued and treated differently in different cultures and at different times. Compare, for example, the way children are welcomed in Spanish restaurants or at Asian celebrations, while other communities show only grudging tolerance. Children across the world have been variously regarded as innocent, or deliberately mischievous; needing harsh or lenient discipline; part of the workforce or encouraged to learn through freedom and play. And patterns are constantly changing. Ehrenreich and English compare childhoods in the US today with those of the colonial period (1600–1775):

_Today, a four year-old who can tie his or her shoes is impressive. In colonial times, four-year-old girls knitted stockings and mittens and could produce intricate embroidery: at age six they spun wool._ (1979, pp 185–86)

Gender, too, has played its part as girls continue to be valued differently from boys in various societies.

If disabled adults are at risk of being made invisible, disabled children are doubly so – largely through stigma and institutionalisation. This is dramatically true in parts of Central and Eastern Europe (Browne, 2005). With the economic decline following the collapse of the Communist system, the proportion of the region’s children in institutional care has increased, with disabled children particularly vulner-
able. Poverty, stigma, poor community support and a belief that the state can care better than families have forced parents in crisis to place their children in institutions as the first, ‘best’ and only option. Often there is little hope of their ever leaving institutional care. If they do stay at home, disabled children are likely to miss education and to become socially isolated.

Nearer to home, disabled children are also scandalously invisible. So much time has been spent arguing about definitions of disability that serious and comprehensive data-collection has been abandoned. Of the studies that do exist, some focus on apples, others on pears, thus leaving comparative analysis open to misinterpretation. What does seem certain, however, is that outcomes for disabled children across a range of areas fall short of those for other children. Disabled children tend to have:

- lower educational attainment;
- poorer access to health services;
- poorer health;
- poorer employment outcomes;
- more offending behaviour.

There is also an unequivocal link between child abuse and disability: disabled children are much more likely to be abused, but less likely to have their names placed on child protection registers. Cook and Standen’s study found that where there are concerns about the well-being of a disabled child, there is 50 per cent less likelihood of a case conference than if the child were not disabled (Cook and Standen, 2002).

Even less is known about disabled children in public care, except that they are over-represented in comparison with their not-disabled peers, even if they mainly enter care for reasons unconnected to disability. Of those children for whom disability is the principal reason for becoming looked after, 20 per cent are on legal orders and 80 per cent are ‘accommodated’ under voluntary arrangements, with the more profoundly disabled children in the latter category. Voluntary agreements between agencies and parents, whatever their other merits, can confound the search for a family placement. Although the Children Act 1989 usefully defines disabled children as ‘children in need’, its emphasis that they are ‘children first’ has resulted in a view that disabled children should be treated like all other children. Unfortunately, this has the unintended effect of discounting the additional needs of many disabled children, so reinforcing their invisibility.

The research report Surveying Adoption (Ivaldi, 2000) provides an insight into adopted disabled children. Ivaldi found that of children who had been adopted, 40 per cent had some degree of disability. Later studies have found that 11 per cent of all children awaiting a ‘permanent’ placement were disabled, and that between four per cent and seven per cent of children placed for adoption and 11 per cent of children placed for long-term fostering had a ‘significant disability’ (Rushton and Dance, 2002, p 69; Simon and Dance, 2006, p 1). It therefore seems more likely that a significantly disabled child will find permanence through fostering rather than adoption, a factor which is reflected neither in children’s profiles nor in individual planning.

Recent research by Mooney et al (2008) notes the continuing dearth of comprehensive data about disabled children. As a minimum, the following information is required if agencies are to plan services and offer a genuinely inclusive service to disabled children:

- the number and profile of disabled children in care, whatever their ‘primary need’ code;
- their legal status;
- their living arrangements;
- the extent to which disabled children are referred to family-finding teams;
- the pathways to permanence which disabled children take;
how long disabled children wait for a placement;
the degree to which disabled children’s legal status has an impact on family-finding.

If disabled children are largely indescribable to researchers, they are also invisible in the childcare research literature. The titles of the few studies of disabled children tell their own story:

- Gone Missing
- Still Missing
- Don’t Leave Us Out
- Seen but not Heard
- The Silent Minority
- On the Edge
- Valued or Forgotten?
- Left Out of the Picture.

Moreover, disabled children do not feature even in the index of most social work publications and rarely in the bibliography. Disabled children are both subsumed under the general child population (and their needs are therefore not identified), or they are regarded as somehow separate from other children and again at risk of being overlooked. Even staff on children’s disability teams tend to work more with the family than with the child her/himself.

Invisible people have no voice. When care is taken to listen, children recount a compelling narrative (Robinson and Stalker, 1998, p 145):

I am excluded from so much and I am so lonely and have few friends. (20-year-old)

The biggest barrier is that I’m not allowed to go out on my own or with my friends. There is always an adult with us. (16-year-old)

The campaign Every Disabled Child Matters talked to disabled children and young people and found that the three things they wanted to change most were:

- to have more fun things to do;
- to change negative attitudes to disability;
- to make it everyone’s right to get a good education.

In everyday situations, people’s inability to connect with those who have communication difficulties makes life very hard. Imagine how much worse it is for disabled children in care when life-changing decisions are being made on your behalf without even an attempt to understand your views:

In only 12 out of 66 cases presented to the [Resources] 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 communicate and therefore her view is not available.’ (Joseph Rowntree Foundation, 1998)

Despite the United Nations Convention on the Rights of the Child, which came into force in the UK in January 1992, a recent report (Committee on the Rights of the Child, 2008) cites a number of areas where disabled children still lack fulfilment of their most basic rights. Among these are the right to express views, the right to access health services and the right to play and leisure.

The tide may be turning a little with new legislation and resources: a recent government initiative, Aiming High for Disabled Children: Better support for families, provides a properly resourced long-term plan for disabled children to the tune of £430 million new money. This is good news. However, there is some way to go if disabled children are to be a full part of the Every Child Matters agenda. The Council for Disabled Children’s campaign Every Disabled Child Matters must be congratulated for keeping up the pressure.
Innovations
In its Strategy for 2008–2011, Lives Changed for Good, the British Association for Adoption and Fostering (BAAF) has committed itself to campaigning around the unacceptable delays experienced by children with disabilities who enter the care system. One of its projects, the Opening Doors Disability Project, has sought to understand why disabled children wait a long time for a permanent new family and to develop more effective ways for agencies to make placements, thereby opening the doors of family placement to disabled children. The project has tried to promote an inclusive approach that sees the disabled child as an individual child who has some specific needs – thus removing the taboo of disability.

It had become very clear that the process of family-finding exposed disabled children to particularly pernicious forms of discrimination. Adoption and fostering is an area of work where families are being artificially constructed and where choices are being made about the intrinsic value of human beings. It seemed that attitudes to disability in this area of social work were exceptionally problematic.

Research by Ivaldi (2000) found that prospective families are less likely to want disabled children. It showed that, whereas 69 per cent and 83 per cent of prospective adopters declared they would take a child who had been sexually abused and physically abused respectively, only 13 per cent and 21 per cent would consider children with mental or physical disabilities. It was fairly clear that the old prejudices and misunderstandings are still operating.

Another problem is that linking the waiting children with approved adults relies on a potentially crude system where staff match a ‘category’ of child (based on age, background, disability, etc) with a ‘category’ of potential parent who, as in Ivaldi’s research, express a hypothetical view about the kind of child they believe they can care for. With disabled children, the sub-text is frequently, ‘We don’t want one of those.’ Thus potential links are being ruled out, based on stereotypes, before any individual child can be brought into the frame. The irony is that one prospective family would never be required to take on disability as a whole, or even the whole range of any particular condition. Yet somehow each individual disabled child is being swept aside in generic descriptions.

The Opening Doors project has argued that the best way for a child to find a family (especially a disabled child) is if families themselves see and respond to actual children: professionals should just let the magic happen. Therefore, adopters’ approval should not be restricted. The Practice Guidance to the Adoption and Children Act 2002 (Department for Education and Skills, 2006) reinforces this view: in essence, adopters should be allowed to be open to any child.

Thus, more links may be achieved if there are direct ways for prospective carers to learn about individual children – by responding to excellently written profiles, seeing photographs and videos, and even meeting children. Encouraging that first spark of recognition and helping families to find a way round the stereotypes and to connect with a real child could provide an answer.

To this end, much of the Opening Doors project work has focused on exploring and promoting these direct methods. One result has been the establishment of SeeMe Films, a family-finding service that uses video as an effective way of conveying a rounded picture of a child. Using film, disability can be presented as a part of a child and not as the whole story. For some children, this may be the only way they will find a family.

Other initiatives have included countrywide promotion and training on the development of video profiling events, where a small film of each waiting child is shown in a cinema-style presentation to an invited audience of prospective adopters and carers. The results are encouraging. This model is
currently being extended by testing the use of ‘placement parties’ where prospective families actually join in activities with a group of ‘children who wait’, and where, again, magic might happen. The project is also exploring the extension of *In My Shoes*, the computer-assisted interview through which children, including those with limited communication skills, can be helped to express their wishes and feelings. All these initiatives can be viewed on the website: www.openingdoors.baaf.org.uk. Many agencies are enthusiastically and successfully embracing these ideas.

**What next?**

There are inevitably continuing frustrations in the quest to get more disabled children permanently placed if they cannot return to their family. Five issues in particular are worthy of more attention:

**1. Inclusion in permanence planning**

There is anecdotal evidence that the planning trajectory for disabled children may be different from the pathways of not-disabled children. Faced with the disheartening supposition that a suitable family might not be found, social workers may not be actively pursuing permanence for some disabled children. The Independent Reviewing Officer’s role is crucial here and it is suggested that they might explore this issue in their area.

**2. Institutional care**

There should be ongoing concern for those disabled children growing up in institutions (such as boarding schools) whose contact with home is so attenuated that they have lost all sense of family life. These children have for too long been outside the safeguards of the Review system and although new legislation is beginning to address this, continuing vigilance on their behalf is essential (see Burns, 2009, pp 9–11). All professionals who come into contact with an institutionalised child should ask themselves these two important questions:

- Does this child have a sense of home and family?
- Who is monitoring this child’s long-term needs?

If either answer is unsatisfactory, action should be taken.

**3. National Adoption Register**

While the Adoption Register’s achievement in linking black and minority ethnic children, sibling groups and older children should be celebrated, it has not yet made a big enough impact on the numbers of disabled ‘children who wait’. This is unlikely to happen until the Department for Children, Schools and Families (DCSF) is persuaded to modify the Register’s contract to accommodate permanent fostering. Many adoptions of disabled children are the result of relationships that began as permanent fostering – but the link has to start somewhere.

**4. Developmental delay**

One of the major barriers preventing children from having families is the increasing incidence (in part because of maternal substance misuse) of developmental uncertainty and developmental delay. Very young children who are thus described seem to fall somewhere between the small number of adults who definitely want to care for a disabled child and the vast majority who will not take the risk. The label seems to blight these children until they are either old enough to catch up or until there is a definite diagnosis. By this time, because they are so much older, no one wants them anyway. More understanding of these vague terms is needed, along with more nuanced descriptions of the implications for each child. Advice from paediatrician colleagues is necessary to take this further.

**5. Disabled applicants**

Despite the fact that there is a need for more people to come forward for all children, disabled applicants are treated woefully badly. Even if they are
approved, they are then avoided by social workers seeking a match. Although hidden behind a smokescreen of supposedly legitimate excuses, the reasons for discounting disabled people as parents for children needing families are often based on pure prejudice. Some suggestions about what might be useful for disabled applicants in their quest to be matched can be found on the website: www.openingdoors.baaf.org.uk.

Conclusion
One of the main aims of BAAF is to ensure that children grow up in families. Until the mid-1970s disabled children were rarely placed in foster care and hardly ever considered for adoption. Argent writes:

When babies with even a slight impairment were relinquished by their birth mothers, ‘unfit for adoption’ was stamped on their files. (1996, p 1)

This now seems unthinkable. Despite current shortcomings, practice has come a long way since those early days of family placement, and achievements should be celebrated.

But there is still some way to go. The more marginalised the child, the greater the professional responsibility. It is not acceptable for already disadvantaged children to stay in temporary care or in institutions, however devoted particular carers may be. Prejudices must be confronted, new ideas embraced and risks taken in pushing forward the boundaries of family-finding. As the North American pioneers of adoption parties have said, ‘Children stand to be hurt as much by the risks we don’t take as the risks we do.’

Most importantly, the taboo which blights the life-chances of so many vulnerable children must be lifted. These children must be brought into the mainstream. No one who works in the field of child care or children’s services must continue to think that disabled children are someone else’s concern. We are all responsible.

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