Disabled children who need permanence
Barriers to placement

Disabled children wait longer than other children for permanent new families and some never achieve a family for life. Jennifer Cousins explores the barriers that make disabled children’s pathway to a family so problematic. It is argued that only with this knowledge can the necessary changes be made on behalf of this vulnerable group of young people.

Over several months during 2003 and 2004, BAAF’s Opening Doors Disability Project ran a series of workshops across England to explore this complex subject with practitioners and carers. This paper includes the many ideas that emanated from these workshops, plus research material and the author’s own views. Problems and barriers emerged in the recruitment, assessment and support of families; in the profiling and placing of children; at management level in the training and development of staff; in departmental structures and in diminished resources. All pervasive is the negativity and discrimination which affects people with impairments. It is argued that everyone engaged in children’s services and family placement has a responsibility to promote the interests of disabled children by tackling the barriers identified here. In so doing, the placement chances for all children will be enhanced.

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Introduction

The central question

Family-finding for any child other than a ‘straightforward’ baby is a challenge but, for ‘disabled’ children, often poses seemingly insuperable extra difficulties. These children are known to wait longer than others for a permanent new family – a problem compounded by being older, black or part of a sibling group (Ivaldi, 2000). If we are to promote the well-being of disabled children in a significant way, it seems timely to analyse what exactly are the barriers that come between them and permanent placement. If we can discover how to improve placement opportunities for disabled children, doors will be opened for all young people who need families.

The Opening Doors workshops

During the autumn of 2003 and the spring of 2004, BAAF conducted a series of seven regional workshops across England to explore this area of practice. We are planning similar meetings in Scotland. Through the BAAF mailing list, we invited those with an interest in the issues – family placement social workers, child-care workers, foster carers, health workers – and were surprised and delighted that at each session nearly 30 people attended from a variety of backgrounds. In total, 200 people came. Our initial expectation that our first meeting (at our base in Birmingham) would attract five people round a coffee table was turned on its head and we realised that we had probably tapped into a significant unmet need: there were clearly dedicated, experienced and enthusiastic people ‘out there’ who had few opportunities to discuss these matters. Having worked in a disabled children’s team myself, I knew that disability can confer marginal status not only upon disabled people but also upon those who represent them. Here was an opportunity to learn from these professionals and to create a national network of like-minded people for support and discussion.

The workshop format comprised an overview presentation by John Simmonds, Director of Policy, Research and Development at BAAF, which picked out the relevant research issues relating to all children. I then highlighted aspects of particular concern to disabled children, including the way children are described and how families are recruited and matches made.

The workshop presentations made particular reference to a paper published in Adoption & Fostering in the winter of the previous year (Cousins, 2003), which had created controversy by suggesting
new ways of matching. The argument in that paper was that current matching tends to rely upon children being categorised into a shortlist of characteristics (a medical model of disability which inevitably highlights impairment) and adoptive applicants being asked to specify hypothetically the ‘kind of child’ they can take. The low number of matches generated by this category-matching through the then Adoption Register database suggested that there were flaws in this method. The argument was advanced that if adopters can be assessed on their general good-parenting qualities, and then asked to identify a particular child whom they feel they respond to, a further stage of assessment can be completed (potentially leading to placement) with that real child in mind. This method has the added advantage that adoption support needs can be assessed specifically.

A child-led approach of this kind puts families, not social workers, in the driving seat and avoids families ruling themselves out in the early stages for a child with whom (once seen) they might fall in love. We know that foster care arrangements frequently become permanent through exactly this ‘knowing-the-real-child’ mechanism (Lowe and Murch et al, 2002, Summary, p 9). Above all, the child-led approach allows a child to become known to prospective carers as a whole child who happens to have a specific difficulty. People who lack confidence with the generic concept of ‘disability’ can be helped to see that caring for this child with this impairment is a manageable and worthwhile thing to do.

The workshop participants were therefore invited to think about these ideas. They then divided into small working groups with the following tasks:

- to identify the barriers that get in the way of placing disabled children in permanent new families;
- to suggest practical ways in which these barriers might be overcome;
- to note any other changes which would make the system more sensitive to both the short-term and life-long needs of disabled children.

Brief presentations were made by each group to a final plenary session and the information was saved, typed up, redistributed to all participants soon afterwards and analysed by myself. It is these ideas which are distilled here, plus some of the research issues and some personal views. The draft of this report has been circulated widely and a number of helpful comments and additions have been taken on board. With more than 200 experienced practitioners focusing together, we have learned a great deal about the central question: what are the barriers that prevent disabled children from having permanent new families?

From what follows we hope that readers will be able to identify how they can contribute to making the necessary changes. This may be in direct grassroots practice within their agency (the recruitment, assessment and support of families, the profiling and placing of children); or at a management level through staff development programmes, rethinking departmental structures or managing resources. The overarching context is the society we live in and the pejorative attitudes towards disabled people that prevail.

Everyone determined to promote the interests of disabled young people who need permanent families has a role to play in tackling the barriers identified here.

 Seen as different: the problem of definitions

In any debate of this kind, one of the fundamental problems is that disabled children are thought about as a separate group. This is patently absurd as each child is different; all looked after children have, by definition, ‘special needs’ and we cannot reliably draw a dividing line between one child who is disabled and one who is not, except in the most extreme instances. Everyone’s abilities

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1 There has always been controversy about the most appropriate terminology. A social model of disability distinguishes between an impairment in functioning and the way in which unhelpful
and disabilities come on a spectrum, differ according to environmental factors and can change over time. Impairment only turns into disability when external circumstances make it so. A person with a hearing impairment would not be disabled in their communication if we all learned British Sign Language as a second language at school. The term ‘disability’ is therefore unhelpful as a defining category. Impairment is part of a person, but not the most important feature – or should not be.

Recruitment of families

A new perspective?

Any discussion about difference leads to the conclusion that family-finding specifically for ‘disabled children’ is the wrong starting point. Specialised recruitment campaigns do draw in a small number of people who have particularly set out to adopt or foster a disabled child – often people with a disabled family member or a professional connection with the disability world. For them, there are fewer stereotypes, less fear of the unknown and more confidence that they can meet the challenges. These people are the easiest to attract because they are motivated, so it is always profitable to target publicity at the places where they may be found and to encourage word-of-mouth networking. Special schools or hospitals, short-break schemes, the child’s existing care or educational network or, as someone suggested, the Nursing Times or the specialised disability press, may all be fertile areas.

However, the general public that does not have these contacts is not so privileged and is less likely to respond to a specific disability campaign. Most people faced with the question ‘Would you be interested in adopting a disabled child?’ would reply with a cautious ‘Well, it depends . . .’ and many would shy away from the idea altogether. For these people, who have no personal knowledge and little confidence that they will manage, disability in the abstract conjures up images of wheelchairs, adaptations to houses, insuperable difficulties with transport, perhaps challenging behaviour – all the negatives. They have therefore ruled out the possibility of taking a child with extra needs right at the beginning of the process, before they even get to know an individual child.

A participant in one of our workshops told a remarkable story. For years her team had run an annual recruitment drive to encourage families to come forward for disabled children. The response was often discouraging: just a small handful. This year, however, the team were delighted by the response – many more people came forward than usual – and they could not account for the upturn. Eventually a colleague pointed to a mistake in proof-reading the publicity material. They had inadvertently missed out the word ‘disabled’. One might have thought that the potential carers would now disappear, but no. They were shown photographs and details of the waiting children and, given the opportunity to hear more about each child’s individual needs (as opposed to a generic image of a disabled child) and the supports which would be available, they felt able to make their applications and begin the home studies.

The lesson is obvious. If we can introduce the whole child before we focus upon the extra needs, we are already overcoming one of the major barriers. Show a family a child who is lively and societal attitudes and arrangements ‘disable’ the person. A simplistic example might be that though many people have poor vision, the majority are not ‘disabled’ because the invention and production of spectacles have contributed towards minimising this common impairment. However, where people have significant vision impairment, the small print in newspapers, on food labels, insurance documents (literally as well as metaphorically) and so on, excludes them from mainstream activity. This problem could be ameliorated at a stroke if all print were larger: the perspective of the social model of disability. The judgemental attitudes and negative behaviour of others often disempower and ‘disable’ people, especially those with a learning or mental health difficulty.

To talk about a ‘disabled person’ therefore becomes a way of highlighting how society fails to enable people with impairments to join the mainstream. It accrues political impact that should be a reminder of our joint responsibility to make things better for all.
lovely, keen on watching birds or collecting worms, and some of the ‘problems’ melt into a truer perspective. It would be very useful if research could analyse the features of families where placements had happened successfully against apparent odds. We have much to learn in this area, but no time to wait.

The broader lesson is that we need to integrate disability issues into all our work; make it part of the mainstream. A recruitment drive to enlist more carers for disabled children may therefore work best if the images in the publicity material show a variety of children, some with visible impairments, some with none – all having a happy time together. All our children are special and all are unique. Above all we have to convey that this is ‘an exciting, fulfilling, challenging way of being a parent – a way of living your life which will make a real difference to children’. If existing carers of disabled young people can reinforce this message by taking part in campaigns and addressing meetings – the so-called ‘horse’s mouth’ – so much the better.

Diversity
Revisiting how we encourage families to come forward for disabled children gives us the opportunity to broaden our recruitment campaigns generally. We know that black children who are disabled are more likely than non-disabled black children to be placed with white families (Simon, 2000) and this needs addressing with some urgency. These children are at double risk because their placement is likely to be managed by non-disabled white professionals who are focusing their energy upon impairment issues rather than ‘race’ (Phillips, 1998, p 166).

There is no reason why disabled adults who apply to adopt should not be considered for the full range of children; but in addition, they may feel that their particular experience in overcoming adversity could be usefully channelled on behalf of a child with an impairment. We must also not lose any opportunity to encourage other groups who traditionally have to cope with discrimination: gay and lesbian people, single and black people and single male applicants. We need as wide a pool of approved adopters and foster carers as possible: it is not in the interests of the 40 per cent of older children who never get permanent families (Hadley Centre for Adoption and Foster Care Studies, 2003) to perpetuate an outmoded vision of what the term ‘family’ represents.

Social work attitudes and skills in interviewing people from marginalised groups must, therefore, be addressed. A predominantly white, female, heterosexual workforce may be most comfortable doing home studies with white heterosexual couples and single heterosexual women.

Responses to recruitment
It is widely known that there is an almost inevitable drop-out among enquirers following the initial contact with the agency and that perhaps as many as nine out of ten people never make it to the application stage. The reasons are already documented, although it has been suggested that at any point, ‘exit interviews’ might prove instructive. (For a good account of this issue, see Sellick et al, 2004, p 90.) In a nutshell, prospective carers must be greeted enthusiastically and should never be left to wonder what is happening. This might be the point at which brief information about all children waiting could usefully be circulated, or ‘welcome meetings’ held where children are featured on videos and posters. For an account of Northamptonshire’s Parents for Children project that uses evening meetings in this way with huge success, see Cousins (2003, p 15). There are also the controversial ‘activity days’ where families and children who are each ‘waiting’ get together to have fun (see Argent and Kerrane, 1997, p 34); and the current feasibility study by BAAF to look at featuring children on the internet. We may recoil at some of these ideas, but if

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2 I owe this quotation to Professor June Thoburn during a telephone conversation. If only we could convey this sense of enthusiasm in all our recruitment and preparation!
40 per cent of 3–11-year-olds never get a permanent family, we cannot afford to be precious.

**Preparation and training**

All preparation and training groups for potential carers should, as the norm, integrate thinking about disabled children. This is quite a challenge and it is often easier to have a separate session, invite a specialist speaker or the carer of a disabled child and hope for the best. From my experience in the 1980s of running adopter training programmes and adding an extra, voluntary module for those hoping to take a child with special needs, I know that only a few people attend and there are biscuits left over. But it is the rest of the group whom one needs to inform and encourage and empower with positive images and solution-based scenarios. Disability needs to be demystified, to become normal. It should be a standard component of all our recruitment, preparation, training and assessment processes. Disabled carers and social workers (as positive role models) and adopters of disabled children should be contributing to training groups as standard. Information about all the children waiting should be available so the widest spectrum of needs is known and there is no possibility that a child with an impairment is seen as separate. The time for specific preparation comes when an individual child is identified whose care needs can be reviewed in the light of the new family's resources. Many of these suggestions will mean training for all staff right across the board.

**Specialised or integrated?**

But – a final word – balancing this integrationist viewpoint with the need to pay extra attention to the additional requirements of specific conditions requires fine judgement and skill. Integration should not mean that disability becomes invisible once more. There should be no need for specialist children's disabilities teams, but one can understand why they are important. One day, hopefully, they will not be necessary. A group at one of our *Opening Doors* workshops wrote on their flip chart the term 'the politics of specialism'. I presume it was these issues that were being highlighted. In my view this remains a conundrum.

**Assessment of families**

As outlined above, the main thrust of the workshop presentation was that assessments should focus on identifying the underlying strengths and capacities of applicants as parents/carers (Can this person protect and promote the interests of someone else's child?) but that families should not at an early stage be asked to specify the 'kind of child' they can take. Ideally, applicants should remain as open as possible to *all* children and respond to profiles of real children who need families, in BAAF's *Be My Parent* newspaper, Adoption UK's *Children Who Wait* or any format that social workers can devise. If the profiles are well written and the children are presented in the round rather than predominantly as a label – an impairment or a problem – then there is an opportunity for prospective carers to respond to a child as an individual. This involves a considerable culture shift away from social workers taking the lead in identifying children for families, towards adopters finding their own child, a route which we believe will lead to more disabled children being placed.

Once a possible link has been identified by the family, a specific assessment can look at the viability of a match between this real family and this real child – the issue of compatibility. Energy can be focused on developing the applicants' strengths to manage specific needs, and future adoption support can be discussed and organised. Clearly the matching/compatibility report takes on new significance and must be robust. It would be interesting to look at the pro-formas for matching developed by different agencies: our experience is that these reports vary from a few brief paragraphs to an extensive document. The young person's view of the suggested match is also universally missing, an issue which needs more debate.

Traditionally, the assessment of adults has been guided by the BAAF *Form F*. However, it is recognised that the matching questionnaire (the 'tick-boxes') is
problematic and may channel applicants to an unhelpfully narrow range of children. (It is more appropriate to explore issues relating to children and their backgrounds during the applicants’ preparation course and not as part of an assessment.) In the new Form F Part 1, therefore, the tick-boxes have been replaced by a version of the Adoption Register’s matching framework (amended to include fostering issues) which notes in more general terms the strengths of the applicants. Under the new regulations, panels will continue to recommend applicants simply as ‘approved’. If panels believe there is evidence that some restriction would be advisable this is recorded, but it does not become part of the formal approval. This continues to give maximum flexibility to agencies.

In tune with this general perspective, the separate Form F1 Part 3 (for applicants intending to care for a disabled child) is no longer appropriate. The time for specific assessment comes later, when a particular child is identified.

Agencies are sometimes tempted to place the youngest and most straightforward child with the most flexible and resourceful couple. This is not in the overall interests of children. Children with impairments, and especially those with severe health problems, are more likely to be placed with a single person (Ivaldi, 2000, pp 90–92) because of what might unfortunately be described as ‘market forces’. Research shows that single carers have a very good track record as carers (Owen, 1999) and for many disabled children this may be the right match. But it is important that the system is rigorously child focused throughout and that resourceful applicants from all lifestyles are used to children’s best advantage.

In the regrettable absence of any research evidence about how the process of linking actually works, the debate about the effectiveness of different systems of assessment and matching continues.

Support to families
In accepting the reality of much impairment, we must note a potentially wide range of supports that caring for a disabled child might require (Beresford et al, 1996). Participants in the workshops strongly expressed the view that the provision of ongoing, reliable, as-of-right support is critical for anyone contemplating adopting a disabled child (see also Argent and Kerrane, 1997, p 27). It is particularly critical that the support is appropriate for families across a range of cultures. We know from research that black and Asian families with disabled children do not receive an appropriate level of service and are, for example, under-represented as users of family-based short-break schemes (Sachdev and van Meeuwen, 2002). The Prime Minister’s Strategy Unit Report (2005, p 103) also acknowledges a considerable level of unmet need among minority ethnic parents with disabled children, including a lower take-up of benefits, possibly associated with a shortage of interpretation facilities in some areas, inaccurate cultural assumptions and inappropriate service delivery. If this is generally true for the minority ethnic community, it is likely also to be true for black families who adopt.

Some agencies have appointed welfare rights workers to help parents through the maze of the state system (a welcome initiative), but social services policymakers, senior managers and budget holders need to be on board too, and all council departments need to work cooperatively in the interests of the child. The relationship between housing and social services, for example, has been notoriously unfriendly, but a truce is vital. Joined-up government is crucial. Families want to expend their energies upon the child, not upon fighting a system which is adept at passing the buck.

It is also important that the support is:

- signalled right from the start;
- assessed in relation to a particular child as quickly as possible;
- guaranteed.

Instead of vague concepts (what does ‘support’ actually mean to the person in the street?), campaigns should itemise in concrete terms the kinds of help (for both adults and children) that may be available. This will include:
✓ finance (including some loss-of-earnings)
✓ education
✓ health provision
✓ medical information
✓ short breaks
✓ equipment
✓ transport
✓ housing and fast-tracked extensions/adaptations
✓ a ‘sitting’ and overnight service
✓ parents’ groups
✓ individual mentoring/‘buddy’ arrangements
✓ after-school clubs
✓ telephone lines for crisis support
✓ domestic help
✓ access to professionals and other carers
✓ advice and information
✓ training.

All these things should of course be available in each area: postcode differences should not be permitted.

The Chancellor’s Child Poverty Review, announced in 2003, has led to the recent introduction of national standards aimed at long-term and sustained improvement in children’s health. Standard 8 of the Children’s National Service Framework, entitled Disabled Children and Young People and those with Complex Health Needs, will, it is hoped, make a significant contribution towards the care of families under stress through ensuring both the earlier identification of impairments and, crucially, more responsive support services.

Long-term support into adulthood
It is of particular importance that information about longer-term support into adulthood is available on request. This is highlighted repeatedly as one of the biggest barriers to the adoption of disabled children and probably one of the most difficult to overcome, involving as it does a degree of continuity which the state seems unable to deliver.3 Families who reach the point of considering the future care of a young person who may not become independent are often concerned either that their existing children or wider family may be coerced reluctantly into responsibilities or that the state will somehow fail their vulnerable adopted child after their own death. Answers should be available; guarantees about continuity of care and provision should be in place from the beginning.

Children with an uncertain future
Contemplating the adoption of a child whose diagnosis or development is uncertain often presents potential carers with an unsurmountable barrier. Absolutely vital are regularly updated medical assessments that are communicated in accessible terms to both social workers and prospective families. Uncertainty is paradoxically experienced as worse even than knowing about limited life span: the emotional burden can be unbearable, especially as it may re-awaken earlier experiences of loss and grief. Establishing a relationship of trust right from the start and guaranteeing unlimited, sensitive and ongoing agency support may be the only way to create such placements.

Profiling and featuring children
The art of profiling
It goes without saying that no profile can be written without a detailed knowledge of the child, based on a robust assessment combining the carers’ views, the child’s wishes and feelings and current medical information. A diagnosis may not always be clear, but whatever is known must be told to social workers, panels and new carers (BAAF, 2002).

Some agencies are investing in a Child Appreciation Day,4 which is an impressive way of building an understanding about a

3 The Social Care Institute for Excellence (SCIE) is funding a new project called ‘The Road Ahead’ aiming to answer common questions on transition such as how to access direct payments, use public transport, find work and so on. See www.scie.org.uk/publications_corporate.asp for their Spring/Summer 2004 newsletter that gives more details.

4 This is a whole-day meeting which has the remit of building a complete picture of the child. It can be valuable before family-finding although is perhaps best timed for when a family has been
child so that future planning is well founded. In ensuring that the child’s views are represented throughout the whole process, extra care and skill are needed with children who have learning or communication difficulties.

Just as we see the danger that families’ hypothetical wishes may become fixed on file and thus prevent possible links, there is a parallel risk that a child too is reduced to a brief data-set of immovable characteristics. Social workers are now usually punctilious about conveying, in a very tight word limit, the ‘problems’ that a particular child might bring, but they sometimes fail to portray the child in the round. The salutary lessons of the ‘Essex case’, where adopters claimed damages from the local authority for failing to tell them the extent of the child’s difficulties, has heightened awareness about giving full information to adopters. This could lead to undue weight being given to impairment and its consequences.

In writing a profile, words are wasted, in my view, on the kind of family required, and unnecessary barriers are erected. Why say ‘two-parent family’ when this rules out single carers with skills and supports? Why say ‘must be the only child’ when some families might genuinely have a family structure which would work for this child? Why say ‘must be patient, tolerant, child centred and able to set clear boundaries’? Surely we want all families to have these qualities. We do, of course, want families who match the child’s ethnicity, but where agencies have genuinely explored every avenue exhaustively and no same-race options seem to be emerging, we have to judge at what stage to open the doors to a wider ethnic range, and develop sensitive assessment tools for this. And do we need, at that early stage, to be rigid about adoption or permanent fostering? Is this not something that could be looked at when we have a choice of families? One colleague wrote:

The priority is locating a family who might meet the child’s needs and then finding a legal route that is congruent with that child’s needs.

This seems to make eminent sense.

In a small study currently being analysed, I looked at what had happened to 18 of the most profoundly disabled children featured in Be My Parent in one month in 2003. One child’s profile stipulated that he needed a ‘black two-parent adoptive family where he would be the youngest child’. Two years later, this child still has no placement (indeed, has had no interest expressed by prospective carers at all), yet his social worker is adamant that these requirements should remain in the profile. It is my fear that this rigidity may have denied this child a family, particularly as we know that children from minority ethnic backgrounds are more likely to find permanence through fostering than adoption (Lowe and Murch, 2002, p 143). Research shows that many single adoptive applicants are black (Owen, 1999, p 30; Ivaldi, 2000, p 92), but data on single black foster carers are more elusive. Nevertheless, it seems wise to keep the options as widely open as possible.

Similarly, very complex, prescriptive contact arrangements can deter expressions of interest right from the start. Where the disabled child is accommodated and social workers feel deeply sorry for the parents’ plight and their wish for high levels of contact, the child’s best interests may become sidelined. Most sensitive adopters will do what is helpful identified but before introductions begin. The Child Appreciation Day is attended by as many people as possible who have detailed knowledge of the child: past and present carers; social workers (particularly those who have worked with the birth family prior to the child becoming looked after); perhaps a teacher, paediatrician, therapist and so on. It is vital that the prospective new family should attend so that they are as fully informed as possible about the child. An independent chair helps participants to develop a chronology of the child’s experiences from (ideally) conception to the present day. Patterns and new understandings emerge which then form a sound basis for future planning and parenting. BAAF consultants can be commissioned to chair these meetings.

5 For a full explanation of this case by Deborah Cullen, Secretary of BAAF’s Legal Group, see Adoption & Fostering 28:1, Spring 2004, pp 78–80.
for the child as contact needs change over time, but may never even begin to pursue an interest in the child if the logistics of contact seem to present a complication too far.

If in the profile more space is released for a deeply individual, well-crafted, realistic, up-to-date description which includes what it is which someone really likes about this child and what the child can do as well as can’t do in an ordinary family environment, we have more chance of attracting a new family. The child’s view of her/himself, their wants and needs and the foster carer’s own words are very important and will bring the profile to life. Anything which we can include at this stage that gets away from the stereotype of insuperable difficulties will be helpful: this child can live in an ordinary house in spite of some mobility difficulties; this child’s foster carers have found it easy to manage the feeding tube; this child is learning really well how to use the necessary creams and lotions for his eczema. It should go without saying that the person compiling the profile must have a repertoire of communication skills, know the child inside out, learn from the day-to-day carers and produce material (including the Form E) of a very high standard. Presentation in today’s world is extremely important. These are essential, not add-on requirements.

Finally, an-out-of-date profile damages the child’s chances of a family. Particularly with disabled children, things may change quite quickly.

**Featuring children**

A word is necessary about the power and symbolism of photographs. However ambivalent we may be about colluding with society’s discriminatory values promoting ideal beauty and perfection, the right photograph can make or break a child’s chances of finding a family. We need to consider whether the photograph conveys an accurate ‘message’ about the child (liveliness, vulnerability, gentleness, solemnity and so on), as different people will find different characteristics appealing. We have witnessed how one child whose photograph unintentionally signals an arrogant lack of interest in the whole process has never, over many months, triggered any enquiries. This child may never have a new family. Videos, of course, are equally powerful (see below under Staff development).

Once the profile is crafted, the photography and video completed and the child comfortable with the results, the information should be circulated as widely and as creatively as possible. We ignore the major media and the internet at a cost. The budget strategy that delays searching out of district is not morally justified. Building networks and links with neighbouring agencies can only be good, despite the interagency fee penalties for such co-operation. The considerable increase in referrals to Be My Parent in the last six years, however, (from 231 per issue in 1998/99 to an average of 350 per issue currently) suggests that agencies are able to be more proactive in looking widely than was formerly the case. Indeed, Be My Parent has had to increase publication from six to 12 issues per year since 1999. The minority ethnic press has also been widely used and the Faith press perhaps less so. Some participants in the Opening Doors workshops told us of new and imaginative ways to feature children, the most outlandish being Farmers’ Weekly for a child passionate about the countryside. And why not?

**Placing children: pathways to permanence**

*Adoption and permanent fostering*

Plans for children (especially young children) are often weighted in favour of adoption (Lowe and Murch, 2002, p 45). The Government is enthusiastic, targets have been set and the research on adoption outcomes is broadly favourable (Sellick et al, 2004, p 108). Many disabled young people who are blessed with that decision, however, often wait a very long time for a family. The widespread perception that, for the new parents, adoption means being left to manage by yourself is hard to shake.

Trust in adoption support is crucial. Until agencies develop their assessment-of-support-needs procedures and people believe that they will ‘deliver’, many
potential carers will only feel secure with fostering. This is entirely understandable. Although permanent fostering has in some quarters been seen as second best, particularly for younger children (a view which is challenged by research such as cited by Sellick et al, 2004, p 62), it seems unreasonable to withhold this option from children who may end up waiting much longer for some ideal adoptive home. Lowe and Murch, for example, discovered that ‘it took, on average, twice as long for children to be matched with adopters as with long-term foster carers’ (2002, p 106) – this was all children, not only disabled children. There are additional issues for black children, particularly older black children, who may be less likely to find a permanent family through adoption (Clifford et al, 2003).

In my view, and the view of many workshop participants, agencies would do well to reconsider the plans for some children for whom it may be more realistic to seek permanent families through fostering. Some of us regret the passing of ‘long-term fostering with a view to adoption’, which at least gave unconfident families the chance to test the water and still provided a child with a permanent home. Recognising that there can be a creative continuum between fostering and adoption may reduce the barrier to permanence for some children, and an exploration and redefinition of the distinct terms ‘long-term fostering’ and ‘permanent fostering’ would be helpful. Perhaps special guardianship will have things to offer too.

For a very helpful discussion of these issues, see Chapter 3 of Schofield et al (2000) and Clifford et al (2003) who in particular explore the differential use of adoption and fostering between authorities.

In caring for a child who has extra needs that have major, continuing financial implications, it is entirely unrealistic to believe that a wide pool of families can be recruited without financial and other guarantees. Agencies are pressurised through fiscal imperative and target-setting to promote adoption but this in itself may be creating a barrier to permanence for some of the more difficult to place children. (The Personal Social Services Performance Assessment Framework indicators should arguably be clearer about the value of permanent fostering and it might have been helpful had the Public Service Agreement target to increase adoptions included permanence through fostering.)

In a nutshell, for some children there can only be two choices: either the child’s adoption plan changes to fostering or adoption must be trusted to deliver the same level of support as fostering.

### Siblings

The issue of placing siblings where one child has an impairment stretches family-finders to the limit. There is sometimes pressure to split off the disabled child in order, it is believed, to give the other children a better chance to join a family. Sometimes having separate adoptive families does at least ensure permanence for all the children, although it is vital that there is good-quality contact between them. However, I would be concerned not only about the possibility of siblings losing touch with one another but also about the message which such practice sends to each child: if you somehow fall short of perfection, you can be discarded and left to your fate. No child, whether disabled or not, should be shown that this is acceptable.

### Legal status

Many disabled children are looked after as accommodated children, not on care orders: the state has no reason to intervene but the parents, as a last resort, request accommodation.

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6 The 50 indicators of this framework include CF/C23 ‘Adoptions of children looked after’ and CF/D35 ‘Long-term stability of children looked after’. The adoption indicator refers to the target set by the Public Service Agreement to increase the numbers of children adopted from care nationally by 40 per cent by 2004–05 and by 50 per cent by 2005–06. This does not of course recognise the many children who achieve permanence through fostering. The ‘long-term stability’ target does not measure children placed for permanent fostering, which appears to go unrecognised by the PAF.
Rena Phillips, in a particularly helpful article (Phillips, 1998), has pointed out that children on care orders have a much greater chance of being placed with a ‘substitute family’. Although the local authority has a duty to review the accommodated child’s case at regular intervals and, at the four-month review, to consider a permanence plan, it is often difficult for the local authority (with no share in parental responsibility) to move things forward if the parents object or procrastinate. Although unable to care themselves, some parents of disabled children, for a variety of sad and complex reasons, cannot agree to permanence with so-called strangers. The result – a lengthy period in temporary care and possible legal battles – is not in any child’s best interests and workers need support and training to ensure that disabled children in this situation are not doubly disadvantaged by being in semi-permanent limbo.

A further complication can arise where the birth family, still with full legal responsibility, plays a major part in choosing a new family while the child remains in temporary foster care, a situation which, in one example from my study of 18 disabled children, has continued for at least two years. When I tracked the family-finding for this little girl, the birth family had turned down at least two sets of prospective adopters, with the social worker resolutely committed to, in her words, ‘working in partnership with the parents’ (see also Phillips, 1998, p.161). It is doubtful whether this child’s best interests are being served by this arrangement.

**Children in residential special schools**

Another situation where the child’s legal status is significant is where a disabled child has a place in a residential setting (more likely than foster care for looked after disabled children). Those in social services (or jointly funded) residential schools are ‘looked after’ children and are protected by the Review Regulations 1991 (see Cullen and Lane, 2003).

However, some parents of disabled children choose boarding schools run by education, and respite breaks with health providers, partly in order to avoid the involvement of social services and its associated stigma. Despite the duty on these establishments to inform social services after three months that a child is living with them, it is widely acknowledged that the follow-up is less than rigorous. Some children in these circumstances, whose well-being falls outside the monitoring provisions of the Review Regulations, can therefore spend long periods away from home without anyone questioning whether they continue to have a real sense of family life (Morris, 1995 and 1998; Morris *et al.*, 2002). One research study shows that two-fifths of these children were not visited by their parents and 25 per cent had had no (and some almost no) visits either from or to home (Department of Health, 1998).

Disabled children are, in addition, multiply at risk of various forms of abuse in residential establishments (Utting, 1997), particularly where they have a communication impairment or learning difficulty.

Because parents remain in full legal control and there is little social services monitoring, adoption or an alternative family is rarely considered.

The main lesson here is that there may be a group of children who desperately need to be given a sense of permanent family life, but who fall outside the usual remit of family-finding services. In some instances, children and families teams, (and especially children’s disabilities teams) have a responsibility to intervene where this will be neither asked for nor welcomed by parents.

**Staff development**

**Awareness**

The need for training about disability and the promotion of the social model of disability run as common themes throughout this paper. The pervasiveness of discrimination towards disabled people, despite the Disability Discrimination Act of 1995, is shocking. The term ‘disabled’ has assumed negative connotations; the word ‘invalid’ means not only ‘disabled by illness’ but also ‘not valid’, a chilling association. One regrets that the
Government, alongside their welcome enthusiasm for adoption, could not spearhead a national programme of disability awareness so that inclusion could become embedded in our culture.

Each of the Opening Doors workshops emphasised the necessity for awareness programmes to be offered to all staff, councillors, trustees, panel members, medical advisers and carers; and for any training programme for social workers or courses for applicants (both pre- and post-approval) to adopt an inclusive approach. As suggested above, prospective carers should be exposed to the issues of disability throughout the process. Inviting adults with a range of impairments and existing carers of disabled children to contribute to training sessions and conferences would provide much needed role models and would give confidence to the wary. It is rare to see a disabled person on a rostrum and we need to think why.

Awareness programmes cost money, but arguably, if senior management really took on board these messages, the situation could change radically and quickly and the barriers to the placement of disabled children might stand a chance of being dismantled. We must use all our creativity to demystify ‘disability’, to ensure that people with impairments are viewed as individuals and to give confidence to potential carers and adopters that even the most complex situations can be managed.

Communication skills
Specific skills are also needed, depending upon the child’s needs. Both social workers and carers must have a repertoire of knowledge and communication skills if they are to advocate or care for a child with these extra requirements. Life-story training is quite commonplace but fewer courses are commissioned which focus on how to communicate with learning disabled or sensory impaired children.

How to present children
In addition, social workers must be specifically trained if they are to translate the child’s personality and needs into profiles that adequately portray the individual child in a way that will attract the right family (see Profiling and featuring children above). The use of photographs is widespread and videos are increasingly used, often to great effect. But a poor photograph or video is a lost opportunity and it is arrogant to think that an amateur pointing a camera at a child will always produce satisfactory results. We must recognise the expertise of other professionals and learn from them if we are to do the best for children.

Attitudes to adoption
Finally, we were made aware through the workshops that not all childcare field workers believe that adoption works. A jaundiced view is understandable if the small percentage of adoption disruptions or disturbances during teenage years are referred to fieldwork teams. One children and families worker was astounded that the ‘success’ rate of adoption is over 80 per cent (Hadley Centre for Adoption and Foster Care Studies, 2003; Sellick et al, 2004, p 108). She had assumed it to be much lower, a perception that is bound to affect commitment to home-finding. Added to this is the idea that some children (including some profoundly disabled children) are ‘not adoptable’, a view which seems to elicit a range of strongly held opinions. It is additionally evident from Lowe and Murch’s research (2002) that there is a wide variation between local authorities in their promotion and use of adoption, though their study regretfully does not comment in detail on disabled children.

So there is much to be done in addressing staff training needs. Again we come back to our main premise: ‘disabled children’ have different individual needs but they are not a separate group of children. All staff throughout children’s

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7 Ruth Marchant at Triangle Services is one of the most inspiring trainers on working with children who communicate without speech.
services need to understand this absolutely crucial message.

**Departmental structures**

Up to this point, this paper has largely focused upon what might be called day-to-day practice. However, the workshops also brought to light some wider structural issues which we believe will be of interest to readers.

It emerged from the discussions that the way some children’s services are designed, though intended to deliver a better overall service, actually may be working against the interests of certain children.

**Separate children’s disabilities team?**

As mentioned above, a separate children’s disabilities team (CDT) has the advantage of developing skills in disability but the disadvantage that these children sometimes fall outside the more rigorous scrutiny and planning afforded to other children who come to the attention of social services. Workshop participants were concerned that disabled children, who are by definition more vulnerable to abuse, may be overlooked by child protection systems, partly because this is not routine work for CDTs. However, as one group of colleagues pointed out, the specialist advice available from the CDT to other teams and adopters can be used to great effect.

**Child protection and permanence planning: together or apart?**

Childcare teams covering child protection as well as permanence planning can find themselves devoting less attention to the latter. With adoption a relatively rare event in such a team, workers may never have the chance to build the necessary skills. For a childcare worker dogged by child protection concerns in the community to be able really to drive a family-finding effort on behalf of a child (who is, after all, safe and sound in a foster home) is sometimes a step too far. We know of situations where the field worker has presented a Form E to panel never having met the child. It is my belief that some children will find a permanent home only where the worker can devote absolute single-minded resourcefulness to finding a family, advocating for that child as passionately as if she/he were their own.

**Who is best placed to family-find?**

Adoption and fostering social workers often operate as links to childcare teams to take up the baton of family-finding for a child. Last year I talked to several adoption workers to discover what helped or hindered them in their quest to find families for particular children (some of the general issues they raised are incorporated here). It became clear that these are the staff who are probably best placed to take up the case at the earliest opportunity; to get to know the child, the birth family and the foster carer, jointly write the Form E, draft the child’s profile and find the new family. Their liaison with the child’s social worker and the court process is of course important, as is working alongside the fostering colleague who may know the child through supervising the foster home. However, essentially there may be significant advantages to the adoption worker driving the family-finding aspect of the case – possibly from the four-month review onwards. It would be interesting to take this debate further.

**Liaison between teams**

The crucial liaison between teams upon which much effective permanence planning rests can be aided enormously by simple factors such as office location. Some while ago I visited the adoption team in Milton Keynes where a massive

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8 Tameside CDT is developing its role of supporting adoption team colleagues as well as adopters both prior to matching and into placement. Contact Sheena Wooding 0161 371 2060 or sheena.wooding@tameside.gov.uk

9 By this I broadly mean teams (called by various names) where fieldwork social workers deal with children during the various stages from ‘in need’/at risk, to ‘looked after’ and eventually to ‘permanence’. Some departments, of course, split the functions into teams such as ‘intake’ and ‘care management’ and some use semantically challenging titles such as the ‘children looked after team’.
aircraft hangar of an open plan office houses all the teams which have anything to do with child care. Both formal and informal (‘water-cooler’) discussions and negotiations are so much quicker and more efficient in these circumstances. The real challenge for other workers in more peaceful individual office environments is to make sure that distance does not inhibit this networking.

Managing resources
No discussion about barriers to permanence would be complete without an acknowledgement of the central place of adequate resources. For example, if adoption and fostering teams are to drive the family-finding, more staff are needed without reducing the already diminished numbers in fieldwork teams.

So many resource deficits hamper the development of good practice:

- budgets which drive interagency choices and placement decisions;
- serious staff recruitment crises in the large conurbations;
- poor retention of field workers;
- tiny training and staff development budgets;
- slow court processes;
- under-funded fostering schemes;
- small recruitment budgets;
- uncertain adoption support.

All of these factors work daily against the best interests of children who need families and disproportionately against the interests of disabled children. We can but flag this up and trust that the arguments are taken to the places where it matters.

Society’s attitudes
We live and work within a culture that not only fails people with impairments but, recent legislation notwithstanding, also continues to discriminate against and disable them. We know that the commonest question at the birth of a baby is: ‘Is she/he all right?’ and that there are strong pressures to rear a perfect child. Applicants are not exempt from these feelings when considering adoption.

As with other forms of discrimination, we are not individually responsible for acquiring these oppressive attitudes, but we are responsible for challenging them and for developing a more equal and inclusive society. Many of the barriers that were identified in the workshops and are highlighted here have their roots in this widespread discrimination.

But while it is easy to blame ‘society’, we cannot allow ourselves off the hook. There are things that we can do proactively on behalf of disabled children who need families – beginning now.

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