The adoption of disabled children

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Introduction

This Briefing Paper summarises what is known (and not known) from recent key research about the adoption of disabled children. We know from the Adoption Research Initiative (ARi) and a number of other sources that disabled children are regarded as "hard to place" for adoption. We know that there are issues that are particularly pertinent for disabled children for whom adoption is the plan, including the influence of local practice culture on decision-making; the need for clarity and flexibility in assessing disabled children and prospective families; delays at different stages of finding families for disabled children; and support to meet individual children's specific needs within their placements.

The summary aims to stimulate discussion and debate about this group of children and their families (or prospective families) at a particularly important time. The Children and Families Bill 2013, currently before the House of Lords, is taking forward the Government's plans to reform adoption services (Part 1) and services for children with special educational needs (Part 3), which campaigners have argued should be broadened to include disabled children without special educational needs. The debates linked to this Bill have served to underline the inadequacy of currently available statistics and other data needed to understand more about adoption and disabled children.

Underpinning the paper is the view that:

> *... all children, including those with impairments, have a right to be seen as unique individuals. They also have a right to a family – and to make that more likely, potential families must be shown through every means possible that each child is more than a label or diagnosis* (Cousins, 2009).

While this paper's focus is on adoption, it is important to note that there are other placement options that enable permanence for disabled children, all of which can deliver good outcomes for individual children when they are appropriately assessed and supported.

The approach

The paper draws on key research findings on the adoption of disabled children from the ARi. It is also informed by the findings from other research, including a large-scale study of movement within the care system, a small-scale study that specifically focused on the adoption of disabled children, and another study that has looked more broadly at planning for the permanent placement of disabled looked after children. Other sources of information include consultations with researchers, and representatives from the Adoption Register for England, BAAF's family-finding service *Be My Parent*, the Consortium of Voluntary Adoption Agencies (CVAA), and the Association of Directors of Children's Services (ADCS).

After setting out contextual information, the paper considers the ways in which three key stages of the adoption process have been and might be further improved for disabled children: planning for permanence, finding a family, and post-adoption support.

The context[1]

Definitions of disability

Drawing together the evidence on disabled children in relation to adoption is complicated by the variety of ways in which this group is defined. The term "disability" can refer to a range of physical and sensory impairments, learning disabilities or emotional and behavioural problems (Bunt, 2013). In addition, even relatively well-defined conditions, such as cerebral palsy, cover a wide spectrum, meaning that such labels give only a partial picture of what being disabled means for individual children. Behind the definitions of disability are children whose likes, dislikes, personalities and views on their own lives need to be taken into account in the provision of services. It is important that their subjective experiences are not obscured by the use of medical or other terms.

Looked after and adopted disabled children

The uncertainties about the definitions and measurement of "disability" make it extremely difficult to collect data needed to plan and deliver effective services for disabled children (Gordon *et al*, 2000). In England the annual looked after children statistics do not include information about disabilities. It is therefore not possible to determine exactly how many looked after children are disabled.

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[1] This analysis is informed by Dr. Claire Baker's 'Insights' paper Number 11 entitled '*Permanence and Stability for Disabled Looked After Children*' prepared for the Institute for Research and Innovation in Social Services (IRISS, 2010).

Few studies have focused on the particular experiences of disabled children who are looked after – researchers have tended to study them as part of more general studies of the care system. Researchers have attempted to describe the scale of the issues, but have not produced reliable figures because they use definitions of disability differently. The most recently published review of various data sources in England estimated that the proportion of looked after children who are disabled is somewhere between 10 and 25 per cent (Baker, 2007).

Planning for permanence for looked after disabled children

Definition of permanence

Within children's services the term permanence is used to describe the emotional, physical and legal conditions that give looked after children a sense of security and continuity in their placements and with the adults who care for them. Permanence should encompass all those qualities that are associated with a family life that lasts into adulthood and throughout life.

Planning for permanence is part of a broader care planning process that focuses on the long-term goals for looked after children. It involves finding the best arrangement which offers a child a "family for life" and deciding which permanent placement option, including adoption, special guardianship, long-term foster care, kinship care or a return home, is most likely to meet the needs of the individual child.

Pathways to permanence for looked after disabled children

The majority of disabled children in care are looked after because of concerns about neglect and abuse, rather than their disability, although their disability may be a contributing factor. As noted above, to achieve permanence they may follow one of several paths. They may, for instance, enter care for short periods and then return home. Alternatively, they may be placed for permanence under a special guardianship order (SGO), where the carer exercises parental responsibility to the exclusion of all others, usually until the child turns 18. They may move to placements with family or friends secured by a range of legal orders. They may also remain in long-term foster care placements, enter residential care or be placed for adoption.

Baker (2007) studied the pathways to permanence of 596 children in foster care in seven local authorities in England over a three-year period.[2] She explored whether there were any particular issues in pursuing

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[2] This study drew on data gathered for a wider study of foster care undertaken by Sinclair *et al* (2005).

permanency for looked after disabled children. The study concluded that all disabled children were less likely to return home and remained in foster care longer than other 'non-disabled' children.

Adoption for disabled children

In relation to adoption in particular, Baker (2007) found that:
- disabled children who were adopted did so after greater delay compared to non-disabled children.
- children in foster care with learning but not other impairments were less likely than others to be adopted, even after age was taken into account.
- children who were "clearly disabled", by contrast, achieved a greater degree of permanence within the care system than others. It is suggested that this was usually because they had been adopted by their former foster carers or remained in long-term foster care.

Across the sample of children in foster care, adoption occurred in the main for the younger children only and the probability of adoption tailed off dramatically after the age of six. However, the disabled children who were adopted tended to be adopted at a later age than other looked after children. Again, it was suggested that this was because they were more likely to be adopted by their former foster carers.

Permanency planning and practice cultures

Cousins (2009) points out that although there is very little formal consensus about what constitutes "disabilities", family finders across the UK seem to agree that disabled children are "hard to place". In the ARi studies, social workers expressed pessimism about the chances of finding adopters for disabled children who were waiting to be adopted. Where new health information had emerged for children, social workers were concerned that this would "put adopters off". It was difficult for the researchers to know how much effort had been put into recruiting adopters for disabled children or those who had genetic risks, as workers were so pessimistic about the children's chances.

Within the ARi there was also evidence that professionals' decision making about adoption was influenced by local authorities' practice cultures and that staff in different authorities expressed different views about whether a child would benefit from adoption if they had disabilities. The following research on the effectiveness of specialist family finding services in finding permanent placements for disabled children could be used to positively influence practice cultures:

- A study followed up a group of 72 disabled children referred to the Adoption Register for England and Wales. At follow-up, 32 were placed in permanent placements: 21 with adopters and 11 with foster carers under legal orders (Adoption Register Annual Report 2010/2011).

- A study of the placement outcomes for 18 profoundly disabled children referred to BAAF'S family-finding service *Be My Parent* during one month were tracked for 18 months (Cousins, 2006). Twelve were placed for permanence. Of these, six were adopted by existing foster carers and four initially short-term foster placements became permanent. Two children were placed with "new" families. One child returned home to their birth family. The remaining five children were not placed within the study's timeframe.

Finding a family

Finding a family describes the process leading up to placing a child for adoption. Typically, the stages include:

- the assessment of the needs of the child;
- family recruitment – the process of finding potential adopters who can meet the needs of children for whom adoption is the plan;
- linking – the process of identifying a particular family as a possibility for a particular child;
- matching – the process that explores and then confirms potential adopters as having the "parenting capacities" and the home and support to meet the needs of specific children.

The assessment of prospective adopters' parenting capacities and the resources available to them should be subject to exploration, discussion and analysis throughout the entire process.

Assessment of the needs of the child

The assessment of any child for whom adoption is the plan relies on direct work with the child to fully understand their needs, wishes and feelings. This is an important task and requires considerable skill and expertise. Additional skills may be needed for the assessment of children with intellectual, sensory or other impairments and alternative approaches to communication may be required.

Technology can be particularly beneficial in helping professionals to communicate with some children. A small research study carried out by BAAF explored the use of a specially-developed computer-assisted tool called In My Shoes, which helps children and social workers to explore and discuss key parts of the child's life (Cousins and Simmonds, 2011). Social workers who used In My Shoes with disabled children were very positive about the results, and gleaned new information about children's intelligence, ability to engage and their level of understanding and views about their lives.

The assessment of young children may also include addressing what cannot be known or predicted – many children have potential genetic or environmentally generated risks, the detail of which will only be clear in

the course of time. Many assessments will require consulting a range of health as well as social work professionals to establish the best of what can be known from the available evidence. Particular care is needed in the communication of this information to prospective adopters.

Assessment of prospective adopters

The Adoption of Disabled Children study (Bunt, forthcoming) suggests that some prospective adopters may have limited previous experience with disabled children but may be able to demonstrate their interest and commitment to them in other ways. This might include a willingness to gain direct experience of caring for disabled children, undertaking independent research, or showing careful attention to the issues that would need to be considered in caring for children with specific needs.

The *Adoption Register Disability Project* also noted that foster carers for disabled children without previous experience "became experts" in the disability-related needs of the particular child they were caring for, that such placements were generally successful, and that some foster carers went on to adopt the children (Adoption Register Annual Report 2010/2011).

Family recruitment for disabled children

The ARi found that three-quarters of agencies had attempted to recruit families specifically to adopt disabled children (and families for other groups of children who are regarded as 'hard to place'). Cousin's practice guidance (2006) suggests that the recruitment of adopters for disabled children also requires the integration of disability issues into all recruitment drives, for instance, using images which show a variety of children including some with visible impairments. It also suggested that disability should be a standard component of all staff training and adopter preparation sessions rather than a separate section. The guidance also advocates the inclusion of disabled children and their carers in such training and preparation. (Appendix 1 outlines a recruitment strategy introduced by one agency in line with this approach.)

Systemic links and exchanges of information between adoption professionals and specialist disability teams or organisations can have positive effects on the recruitment of carers for disabled children. Such exchanges have led to links between disabled children and prospective adopters. Specialist disability teams and organisations can also give valuable advice about specific conditions, which helps to clarify disabled children's needs.

Linking

There have been developments in linking in recent years, based on greater recognition of the need, particularly for disabled children, to show the "whole" child to prospective adopters in a way that is honest, clear and personal. Cousins (2009) outlined the differences between links generated almost entirely by social workers and those where potential adopters have a more direct role in initiating links. She compared approaches such as social workers identifying families already approved in-house by agencies with approaches that directly involve the participation of prospective adopters. Cousins explained that approaches that allow prospective carers greater involvement in the link are more likely to result in them experiencing a "spark" that leads to them putting themselves forward. The "spark" may, for instance, be a response to a child's personality or characteristics, or a feature that seems familiar or endearing to the prospective adopters.

Adoption Activity Days provide a particularly clear example of adopter-led linking. These are events where approved prospective adopters (or those close to approval), have the opportunity to meet a range of children who need adoptive placements. The events are usually themed and involve activities such as face painting, climbing, craft and soft play, and children attend with their foster carers and social workers. Forty-two children have been placed through the Adoption Activity Days pilot project run by BAAF, including a substantial proportion of disabled children. For example, six of the seven children adopted through the first event in October 2011 had a disability and/or medical condition.

In addition to the introduction of adopter-led linking, there have been other positive developments in linking. One example is that special attention is now paid to the language used in written descriptions (or "profiles") of children needing adoption to ensure that their impairments or conditions are well explained. New approaches have aimed to move beyond the "stark and abbreviated facts" about a child's impairment and instead bring to the fore more individualised, subtle and personal aspects of the child (Cousins, 2009).

Video clips of children have also become a more standard part of the approach, particularly for children who are viewed as the hardest to place or who have been waiting the longest to be placed. An evaluation of the use of video clips on *Be My Parent*'s website found that they increased the number of enquiries from prospective carers by about a third compared to children without a video clip on their profile (Grant 2010). As one prospective adopter explained:

> *The concerns and thoughts we had after reading profiles were dispelled and confirmed, giving us a better and more realistic opinion of how we would cope with the children.*

Social workers in the video evaluation project also highlighted that, if handled sensitively, creating a video allowed children to take part in family finding by directly articulating their needs, wishes and hopes to prospective carers or showing their favourite activities or responsiveness (in different forms) to their carers.

The ARi showed that local authorities often took a sequential approach to the linking process. They looked in-house, then through the local consortium, then turned to other local authorities, and finally to voluntary adoption agencies. There were similar findings from a study of 18 social workers from 16 local authorities who had placed disabled children, with some delays reportedly caused by having to seek permission from managers for each separate method (Bunt, forthcoming). However, findings from the *Adoption Register Disability Project* (Adoption Register Annual Report, 2011/12) suggest that of the 60 social workers interviewed, most recognised that simultaneously pursuing more than one approach to linking leads to better results than using one resource at a time.

Matching

Social workers and adopters in the *Adoption of Disabled Children* study reported that during matching, negative aspects of a child's impairment and its implications were heavily emphasised (Bunt, forthcoming). From the social workers' perspective, this was a way of "testing" whether adopters could cope and were committed, but it could create anxiety for adopters and felt out of proportion to the impairments of the child whom they went on to adopt. Bunt points out that not all adopters will have the same level of knowledge about disability, or feel confident in discussing the needs that may arise from specific impairments or conditions, particularly if these are not described clearly. There are many external factors involved: 'the response to the prospect of adopting a disabled child may depend upon the adopter's exposure to disability issues, the amount of contact they have had with disabled persons and early socialisation experiences that shape how a disabled life is conceptualised' (Bunt, 2013). Prospective adopters who express an interest in adopting disabled children can be supported to gain insight and experience, for example, through children's disability support groups.

Support

Adoption support

Adopted children often need help and support to maximise their development. They will often have experienced separation from people whom they have come to know as their "parents" whether these are birth parents, birth family members or temporary foster carers. They may also have experienced various degrees of neglect and/or abuse or been exposed to pre-natal drug and/or alcohol misuse, been exposed to poor maternal mental health and/or nutrition, and/or inherited a predisposition to mental health problems.

The child's adoptive parents may need the support of a range of routine and specialist services to help with the child's recovery, and to cope with their caring role. The children themselves may need help beyond that offered from within their new families. The support needed may be of a psychological, health, educational, practical and/or financial nature. The families' needs are likely to change as the child develops.

Adoption support for disabled children

Additional and uncertain needs

Adopted disabled children are more likely to have additional needs for support than children who are either disabled or adopted. Raising a disabled child is likely to involve substantial direct financial costs well above those costs involved in raising non-disabled children. But other forms of support can also be crucial to the quality and stability of the placement. These include – but are not limited to – medical information, access to professionals and other carers, housing adaptations, "sitting" and overnight services, respite short breaks, education, help with contact, and services into adulthood (Cousins, 2009).

Another form of support that risks being overlooked for disabled children and their adopters is support for contact arrangements with members of the child's birth family. Baker (2010) argues that although some studies have found disabled children are less likely to have contact, their need is at least as great as that of other children. Planning contact requires careful and ongoing consideration of the specific child's needs. For some disabled children, their social workers may also need additional support themselves to develop strategies that work for children with sensory or other impairments.

Adopted disabled children are also more likely to have a particularly large range of professionals involved in their daily lives. This brings both advantages and disadvantages. The ARi noted that having a fostering or adoption social worker involved might help in advocating for support from health and education agencies. For children with an identified impairment or learning disability, access to additional support (such as the Disability Living Allowance or educational support) may be more straightforward than for adopters seeking support for very challenging behavioural issues without a specific "label".

However, several issues complicate this matter. First, the range and extent of children's needs may not always be recognised in assessments for adoption support made at the point of placement. This applies to all children being placed for adoption, as additional issues emerge, or needs identified previously change over time. For disabled children placed prior to school age, for example, it may not yet be clear whether or how their impairments will affect their education. Second, and conversely, assessments that focus on children's disability or educational needs may not take account of needs arising from their adoption. Health and education professionals may not even be aware of children's adoptive status. Third, provision can also vary enormously across authorities, both in terms of the level of support offered and the extent to which adoption, disability and education services are "joined-up".

The need for clarity about support

Underlying all these issues is one key concern: clarity about support. Bunt's interviews with adopters of disabled children suggest that knowing what *will be* available rather than what *might be* available is vital for prospective adopters, so they can make informed decisions about whether they could meet that child's needs(Bunt, forthcoming). The earlier this information is available, the better.

Similarly, the Adoption Register Disability Project identified that 'creative and early consideration of all avenues of adoption support can help attract initial interest, as well as allay prospective enquirers' fears regarding future resources, e.g. specifying non-means-tested benefit entitlement, equipment, settling-in grants, CAMHS access, adoption allowance, etc' (Adoption Register Annual Report 2011/12). Lack of identified support caused delays for the placement of some children, as initial adoption support packages were not in place before family finding started (Adoption Register Annual Report 2010/11).

A clear link between support and family finding underpins a new Consortium of Voluntary Agencies' initiative called *It's All About Me*. This service aims to recruit, train and support adoptive families for 300 children a year who need adoption and are harder-to-place than others. The children are likely to include disabled children. Assessments of the children's and their prospective adopters' needs for support are made prior to the placement by a specialist team at the South London and Maudsley Hospital. After prospective adopters have been matched with particular children, they will receive intensive training specifically relating to the needs of those children. Training and support will continue for two years post-placement, including a 24-hour helpline.

Support for foster carers to adopt

In the ARi, managers and fostering staff recognised that in many (but not all) cases, the time-limited nature of the transitional financial support for foster carers wishing to adopt created a disincentive to adoption. Some felt this was particularly likely for disabled children. In line with Cousins' (2009) argument, however, it was not just financial concerns but the potential loss of other forms of support that was crucial. As one manager explained:

> The foster carers I worked with always said that the reason they would want to foster is because they would want to have constant access to the social worker, constant access to services.

As noted earlier, adoption by foster carers is an important avenue to achieving permanence for some disabled children. Therefore any barriers to such an option deserve particular consideration.

Bringing research, policy and practice together

The issues outlined in this Paper represent major challenges for all those working with adopted disabled children or disabled children for whom adoption is the plan. To address these, it is vital for the whole sector to engage in continuing open and reflective discussions about best practice. During the course of the consultations, BAAF was alerted to an initiative in Scotland that aims to improve the lives of looked after disabled children (See Appendix 2). Initiatives such as this offer an important way forward by drawing together expertise in research, policy and practice on these very significant issues.

Key points

- The development of effective services for the permanent placement of disabled children is hindered by insufficient statistical information about their numbers and profiles.

- Looked after disabled children are less likely to return home, and more likely to remain in foster care longer than other looked after children.

- Disabled children experience longer delays in the adoption process than "non-disabled" children. They also tend to be adopted at a later age.

- Information about the successes of specialist family-finding services could be used to encourage more optimism about the adoption of disabled children.

- Professionals need support to develop the specialist knowledge and skills required for the assessment of the needs of disabled children and their prospective adopters.

- The recruitment of adopters for disabled children needs to be incorporated into all recruitment drives.

- It is important that the "whole" child is portrayed rather than his or her disability in attempts to link disabled children with prospective adopters.

- Simultaneously pursuing more than one approach to linking children with prospective adopters leads to speedier matches. Resources need to be made available to enable this.

- Adopted disabled children are more likely than other adopted or disabled children to have additional needs for support. There needs to be clarity about what support *will* as opposed to what *might* be available.

- The adoption of long-term looked after disabled children by their foster carers, where appropriate, needs to be encouraged and supported as one way of promoting their sense of belonging and permanence.

Acknowledgements

Adoption Research initiative (ARi) references

The ARi is a group of major research projects that focuses on permanence planning, matching, support for adoptive placements and the costs of adoption. For full details see: www.adoptionresearchinitiative.org.uk

This paper draws on the overview of the initiative's findings that has been published by BAAF:

Thomas C. (2013) *Adoption for Looked After Children: Messages from research: An overview of the Adoption Research Initiative,* London: BAAF.

It also draws on findings from the following individual ARi research reports:

Biehal N., Ellison S., Baker C. and Sinclair I. (2010) *Belonging and Permanence: Outcomes in long-term foster care and adoption,* London: BAAF.

Dance C., Ouwejan D., Beecham J. and Farmer E. (2010) *Adoption Agency Linking and Matching: A survey of adoption agency practice in England and Wales*, London: BAAF.

Farmer, E., Dance, C., Ouwegjan, D., and Beecham J. (2010) *An Investigation of Family Finding and Matching in Adoption,* available from the authors.

Selwyn J., Quinton D., Harris P., Wijedasa D., Nawaz S. and Wood M. (2010) *Pathways to Permanence for Black, Asian and Mixed Ethnicity Children*, London: BAAF.

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Appendix 1 – Recruiting prospective adopters

The *Widening Horizons* initiative, introduced by St. Francis Children's Society, aimed to broaden staff members' and prospective adopters' understanding of disabled children. A social worker within the adoption team led the work by championing the needs of, and challenging the myths about, disabled children *throughout* the organisation. For instance, the agency's literature was audited to ensure that disabled children were represented in a constructive way. The initiative also aimed to encourage all prospective adopters to consider the possibility of adopting a disabled child. For instance, preparation groups for adopters included adopters who were successfully caring for disabled children. Prospective adopters who had not previously considered adopting a disabled child and were willing to consider the possibility were supported to become involved in the work of arts and support organisations for disabled children. The initiative also aimed to boost the recruitment of adopters for disabled children by targeting people who had personal or professional experience of disabled children. At schools for children with special educational needs, representatives from the initiative attended events for parents, staff and volunteers, displayed posters, distributed leaflets, and wrote articles for newsletters. The aim of these various strategies was to encourage parents and staff to pass on information about adoption to anyone in their social network who had an understanding of the challenges and rewards of parenting disabled children.

Appendix 2 – Bringing policy, research and practice together

In Scotland, the Centre of Excellence for Looked After Children in Scotland (CELCIS), the School of Applied Social Science at Strathclyde University, Quarriers Fostering Service and The Fostering Network have been carrying out a successful knowledge exchange programme in order to improve the outcomes for looked after disabled children. To date, they have held one of two symposium events (the next is scheduled for early December 2013), involving a two-day workshop that brought together senior practitioners, social work training, policy-makers, researchers and foster carers to discuss both the challenges and the good practice that already exists. The aim is to identify what actions can be taken to raise the aspirations of all professionals working with looked after disabled children, including through social work training and developing research to address current gaps in knowledge. There is a particular focus on ensuring permanency remains a viable option for disabled children in foster care.