

PRACTICE NOTE 34

THE PLACEMENT OF CHILDREN WITH DISABILITIES

This practice note deals with the permanent family placement of children with severe or multiple disabilities. Disability here refers to a physical, sensory or intellectual impairment, or a chronic disabling medical condition.

Background

Until the mid 1970s, children with disabilities were rarely placed in foster care and hardly ever considered for adoption. Parents were expected to get on with the job of parenting as best they could, and if they couldn't, to leave their child in residential care with the minimum of fuss. When infants with even a slight disability were relinquished by their birth mothers, "unfit for adoption" was stamped on their files.

When change came, it came as it often does in social work with a mighty swing of the pendulum. Inspired by pioneering work in the United States of America (USA),¹ influenced by the seminal British study, *Children who Wait*² and encouraged by experienced adopters, several independent projects were established in the late 1970s which demonstrated that a substitute family could be found for every child with any kind of disability; and that the best families are often unconventional. There were rumblings of "second class parents for second class children", but the critics were largely answered by the increasing number of unusual, successful placements, as described in Catherine Macaskill's research *Against the Odds*.³ Not only did the children often make progress beyond anyone's expectation, but adoptive and foster families reported a sense of achievement and spoke of great rewards as well as frustrations – frustrations that were not to do with the child's disability but with society's disabling attitudes.

Following the groundbreaking work of the specialist voluntary agencies, many local authorities set up their own units to find families for children with disabilities. The work is time-consuming and demands terrific commitment, tenacity and team support. During periods of financial restraints, there is a danger that children with disabilities who are "looked after" by local authorities, will once again be allowed to drift, if both intensive in-house social work and referral to an outside agency are deemed too expensive. This is an unwise view and misplaced saving if a child's or young person's long-term needs are taken into account. Financial restraints should not hold back the placement of a child with disabilities; these children will progress much better with a family and deserve the chance to do so.

Identifying the children who need substitute families

The majority of children with disabilities continue to live in their own homes with their families of origin, for most of the time. They are nevertheless "children in need" according to the Children Act 1989 (England and Wales) and the Children (Scotland) Act 1995 and qualify for a whole range of services to meet those needs, including resources to keep their family together. Potentially, all parents with a disabled child could face a crisis at some time, which they will not be able to handle alone. Birth families should be offered all necessary help to keep their children at home. They may need special aids or adaptations, respite or short-term care, domiciliary services or financial help. Children rarely come into the public care system simply because they have a disability, but some are accommodated by local authorities when parents cannot provide, or perhaps cannot go on and on providing, total or specialist care.

Other children with disabilities come into local authority care along the same route as any other child: family breakdown, sexual abuse, neglect, violence and mental illness put *all* children at risk. The decision to seek a permanent substitute family has then to be based on individual needs, capacities and circumstances, and not merely on a belief that all children are placeable.

Gathering information

Sharing good information is one of the most crucial ingredients for success in any placement. Before information can be shared it has to be painstakingly collected by observation, through interviews and from reports and where possible, visits should be made to those responsible for the reports. Everything has to start with the child and should include:

- discussion with the child's parent/s to learn of their perceptions of the child's needs;
- up-to-date medical reports from the GP and the health visitor, an expert in specific disability and a developmental specialist, with comments from the agency medical adviser;
- school reports, educational psychologist's report, copy of educational statement or record of needs;

- reports from speech, art, play and physiotherapist, as appropriate;
- discussion with other key professionals as indicated;
- detailed family background including medical history;
- photographic record of child, child's family and previous carers;
- child's life story filled out with memories by family and carers;
- an account of the work done to help the child understand and make some sense of what has happened in his/her life and what is planned;
- "a day in the life of the child" recorded in writing or on cassette by current carer;
- significant people in the child's life: contact needs in short and long term and parent's ability to sustain contact and contribute to placement;
- child's ability to attach, need to regress, degree of institutionalisation, experience of separation and loss;
- information regarding any current programmes of care and behaviour management;
- financial support available; it is said to be three times more costly to bring up a child with disabilities⁴

This is no doubt a daunting list preaching a counsel of perfection. But it should go a long way towards an understanding of the whole child and of the child's needs in placement.

Matters for consideration

Ethnicity

Matters of ethnicity and culture must not be overlooked because the focus is on disability or because the child "does not understand". Even children with severe learning difficulties are probably aware of their own and other people's skin colour. This is well illustrated by the case of a black baby with multiple disabilities who was brought up by a white foster carer almost from birth. When he was three years old he was placed with a black single adopter. He took evident pleasure in repeatedly touching his own skin and then stroking his new mother's face. Racism can be yet another difficult area for children with disabilities – they may be less well equipped to deal with it than other children.

Contact

Contact with birth families is as important an issue for children with disabilities as for any children who have to be separated from their parents.⁵ It is never good enough to presume that a child does not comprehend the meaning of relationships and that therefore contact has no significance. On the contrary, it could be argued that only by maintaining continuity can a child with learning difficulties make sense of her world or a child with physical disabilities accept himself as he is.

Some birth parents resist contact because they feel guilty about not being able to cope. Some adopters or foster carers are resentful about parents who could not accept disability or may even have caused it. Carers must be able to take on and deal with the feelings of guilt, inadequacy and loss of the birth parents. Their child will have built up a bond with them, regardless of his/her disability, and will, in some way, show recognition if given the chance of ongoing contact. If both families can be led towards the child's perspective, the birth parents may be comforted to see their child thrive, the new family may feel confirmed as good carers, and the child will be reassured that no-one disappears and that disability does not frighten people away.

Permanent carers should believe that positive contact will enhance a placement; they should not be asked to agree to contact as a condition or as an inducement.

Abuse

Abuse of children with disabilities is hard to contemplate, particularly if the child's disabilities are the result of the abuse. And it cannot be taken for granted that any child is too disabled to be sexually abused. If children who are known to have been abused are placed with new families, they will require expert advice and guidance.⁶ Carers would also need help both in acknowledging their own feelings as carers in addressing painful issues with the child in a constructive way.

Publicity and recruitment

People seldom make an off the cuff decision to foster or adopt a child with disabilities. Prospective carers have to be made aware of the need for permanent families for children with disabilities and the rewards that this can bring. Features in magazines and newspapers create more interest than direct appeals in the advertising columns, and they come free. Birth parents are more likely to agree to an article than to an advertisement, especially if they are encouraged to be involved and if they understand

that the publicity may reach the right family for their child. It is useful to cultivate relations with local reporters and independent journalists who have written about disability. The child's story should be accurate and first names should never be changed; names have a meaning and belong to the chemistry of attraction. Potential carers who respond to a specific child must be able to trust what they have read.

Experience has also shown that one of the most constructive and fruitful ways to recruit carers is through the network of existing carers, and people working in the "caring" professions, for example, residential/hospital units or children's homes.

Potential carers

All sorts of people can become parents for all sorts of children, but what kind of people make a positive choice to offer permanent care to a child with disabilities?

- families who have personal experience of disability;
- families who start by wanting a child without disabilities and then stretch to meet a greater need, usually in response to an individual child;
- parents who have raised their own children and want to go on being parents but are ready for something more challenging;
- people whose religion gives them the motivation and the strength to commit themselves and to persevere against the odds;
- people who do not fear the stigma of disability;
- people who work with, or have worked with, children with special needs.

It is far better to welcome and listen to every one who responds to a child with disabilities than to select on grounds of age, gender, marital status, religion or sexuality. This is not a question of lowering the sights, but of widening the horizons. There are some qualities, however which are worth looking for: a proven capacity to overcome problems, a willingness to adjust to changing situations, openness, the ability to communicate, to stand up to criticism and to fight for rights.

Interagency placements

Although it is best to seek a family especially for each child, it is less time-consuming and more economical to make use of families who are already approved and ready and waiting. Every effort must be made for carers and children to be matched carefully.

BAAF publishes a bi-monthly newspaper, *Be My Parent*,⁷ which contains profiles of children needing permanent new families. Many of these children have moderate to severe disabilities. BAAF has also recently piloted and set up BAAFLINK, a national computerised service which links children with approved carers. Children with disabilities can thus be linked and placed with families who have been approved to foster or to adopt nationwide.

PPIAS (Parent to Parent Information on Adoption Services) also publishes a quarterly newsletter⁸ with photolistings of children with special needs. This reaches adoptive families who may already have adopted a child with disabilities as well as those approved and waiting.

There are set fees for *all* interagency placements; interagency arrangements vary, but the long-term placement support is usually undertaken by the agency which has approved the family.

Adoption or foster care

Adoption is still the preferred way to achieve permanence for many children who cannot live with their own families of origin, and children with disabilities need a family for life even more than other children do. Long-term foster care is less favoured by many local authorities, but it can have a great deal to offer when the plan is to share the care of a disabled child. Much depends on the parents' wish to remain the responsible parents, on the carer's skills to balance the child's, their own and the parents' needs, and on the level of support offered by the agency.

Some families are adopters by nature: they want to become the legally recognised parents; they are ready to make a commitment and to take on the whole responsibility; they want the disabled child to belong. This should not mean that they deny the birth family or the child's history or that they do not celebrate adoption as a very different way of having children.

Other families are more at ease with the idea of foster care. They may not want to have sole responsibility for a child with complex disabilities and may wish to share this with the birth parents who may continue to be involved even if not able to directly care for the child; they may have to rely on the local authority for greater financial support than adoption allows; they may fight shy of legal processes or they may simply come from a community where foster care rather than adoption is the norm. This should not mean that they do not offer permanence, that they are uncertain about taking a

child with disabilities, or that they will not consider themselves the child's primary carers and advocates.

Preparation for permanent care

1 The carers

When prospective carers approach an agency about a child with disabilities, what do they have a right to expect?

- *information and explanation* about the child or children needing families, about the agency, about the assessment process;
- *a service they can use and understand*: no medical jargon about disability, interpreters if appropriate, and flexible programmes;
- *honesty and openness*: the truth about a child's history and prognosis, about how decisions will be made, about problems as they arise, about the limits of confidentiality;
- *training* in groups, individually, and with other family members to cover growth, development and independence in relation to disability; demands and rewards of caring for disabled children; disability rights and benefits (adopters and foster carers who already have disabled children often make the best trainers);
- *tools for self assessment*: exercises to enable prospective carers to judge what they can and what they cannot offer to a child with disabilities, and how their own family will be affected and how it will react;
- *expert advice and guidance* on an identified disability or medical condition, on managing a sexually abused child with disabilities, on special educational needs;
- *preparation for a specific child* including meeting parents, previous and current carers and teachers, finding out about disability services in the neighbourhood, planning aids and adaptations;
- *support*: enhanced adoption or foster care allowances, respite care, child sitting service, access to transport, nappy service, the offer of contact with families facing similar problems and support groups who have experience of caring for children with particular types of disability.

The aim of preparation must be to enable applicants to withdraw as well as to move on. Prospective carers should be encouraged to explore their full potential, but should not feel that they have to prove themselves by taking a child with disabilities. Agencies should be open to exploring the potential strength and specific experience of disability which disabled prospective carers can offer.

2 What do children with disabilities have a right to expect when they must move to a new permanent substitute family?

- *life story work*⁹ to help them understand their own background and disability – no child is too disabled to benefit from this attention if it is offered at the right level;
- *information and explanation according to comprehension*: what will happen and why; who is who; foster care and adoption; continuity and contact with the birth family;
- *preparation for new family*: who are they? Why do they want me? How do they look? Do they know I'm disabled?
- *truthful reassurance*: my mum couldn't manage, how will anyone else? What happens if they can't? What happens if I get sick? Who'll tell them about my fits? Can they speak sign language, mend the wheelchair, rub my back and keep me safe?

If direct work with severely disabled children seems to be leading nowhere, consultation with a therapist experienced in disability would be advisable. (Enquiries can be made to The Council for Disabled Children at the National Children's Bureau, 8 Wakley Street, London EC1V 7QE or The Tavistock Clinic, 120 Belsize Lane, London NW3 5BA.)

3 What do birth families have a right to expect if their disabled child is to be fostered or adopted?

- *respect and understanding* of their feelings including any negative expressions of emotion, for example, anger;
- *information and explanation* about the process, the choices, the experience of other children with disabilities and their placements, the contribution they can still make, their rights and responsibilities, and the prospective carers;
- *support* to make informed decisions, to participate in realistic contact plans, to work in partnership, to grieve and to mourn.

Whatever the circumstances, the relinquishing parents of children with disabilities have a heavy load to carry; it is important that they have a partner, a family, a network, or professional help to share the weight.

Introductions

As the purpose of introductions is to encourage the child to feel secure with new carers and in new surroundings, it must be a priority to keep the nature of the disability in mind when plans are made. It is important that the child is helped as far as possible to understand what is happening and the best way of doing this will require thought and imagination.

Apart from physical considerations of transport, distance, escorts and stamina, what does this child see, hear, comprehend and anticipate? It is no good planning long drawn out introductions for a child who cannot retain an image in the mind – a visually impaired child will have to be familiarised through touch and smell and sound, a non-verbal child may need to make links with music or with food or with the cat. One family spent hours sitting in the bathroom with their new daughter because she became devoted to the sound of the various drains and flushes; she also became devoted to the family while they sat and listened with her.

There can be no rules about the length or the pattern of introductions. Some children with severe learning difficulties will only become confused by repeated visits to the new carers' home, others will need to visit again and again before they feel comfortable. Some children can make the move if they have become used to the new people, for others the new place is more important.

The details of each introduction plan should be agreed in advance with everyone concerned – parents, new family, present carers, social workers and, if at all appropriate, the child. But a precise plan is not a rigid plan; it must allow for rapid as well as slow progress. And it must be closely monitored in order to be responsive to unforeseeable circumstances and unpredictable reactions.

The role of the medical adviser

Children with disabilities usually have complex medical histories and needs. The placement agency's medical adviser can give the following specialist service during preparation and introductions:

- ensure that all relevant health and developmental information is collated and request additional or supplementary medical reports;
- advise the social worker, the panel and prospective carers about the specific disability and implications for placement, interpreting medical terms;
- ensure that all medical records and reports are passed from one health authority to another immediately a child is placed;
- ensure contact with local child development centre and appropriate services, for example, respite.

Post-placement support

The Foster Placement (Children) Regulations and the Adoption Act 1976 and the Children (Scotland) Act 1995 place a duty on local authorities to provide continuing post-placement support for all the parties involved. Children with disabilities and their new families also qualify for a range of services in their own right.

All post-placement work should follow on from the preparation process as part of the normal service, and not as a rescue operation, nor should it dwindle away to twice yearly reviews.

Post-placement work with families who have a disabled child has to be concerned with many practical matters and forms, allowances, appliances, applications, appeals and registrations take up a lot of time. There is a danger that the more painful themes of separation and disability are thus avoided. The support of a social worker experienced in both family placement and disability is paramount. Children with multiple disabilities attract many experts and families can feel overwhelmed. Post-placement work should include liaison between agencies.

Disability will remain a factor to be reckoned with throughout the family's life cycle: births, marriages and deaths; going to school, leaving school and leaving home (if able to pursue independent living) will be crucial times for the disabled child, for the carers and for any other children in the family. Moves towards independence can be particularly traumatic if the young person with disabilities appears to be totally dependent on the carers. The best laid plans for contact have to be regularly reviewed and adjusted to changing needs. The child with disabilities and both families may require support at different stages in order to maintain purposeful continuity.

Children with disabilities will present several challenges to their carers and the quality of post-placement support is as decisive as the quality of preparation and assessment.

Looking to the future

Young people with severe disabilities tend to present more management problems as they grow older, bigger and heavier. Training and preparation for some level of independence is an essential part of the social work task. Employment, housing, access to public buildings and transport, day and residential care and further education are not easy to find and/or utilise. Placement workers, foster carers and adopters have to stand side by side with the birth families of disabled children to press for more and better and integrated services for all people with disabilities.

This Practice Note was prepared by Hedi Argent.

References

- ¹ Sawbridge P, *Opening New Doors*, BAAF, 1975.
- ² Rowe J, and Lambert L, *Children Who Wait*, ABAA, 1973.
- ³ Macaskill C, *Against The Odds*, BAAF, 1985.
- ⁴ Baldwin S, *The cost of caring: Families with disabled children*. Routledge and Kegan Paul, 1985.
- ⁵ Russel P, 'The importance of contact for children with disabilities', in *See You Soon: Contact with children looked after by local authorities*, Argent H (ed), BAAF, 1995.
- ⁶ Argent H, *Post-adoption services for children with disabilities*, Practice paper published by the Post-adoption Centre, 1996.
- ⁷ *Be My Parent*, BAAF.
- ⁸ *Adoption UK*, PPIAS
- ⁹ Ryan T, and Walker R, *Life Story Work*, BAAF, 1993.