Permanency planning for children with Down’s Syndrome  The adolescent years

The recognition that ‘no child is unadoptable’ (Churchill et al, 1979) has been one of the most successful features of special needs adoption. This has led to a growing number of placements involving mentally disabled children (BAAF, 1983). **Kathy Mason, Peter Selman** and **Mike Hughes** report on the third stage of a longitudinal study of 12 children with Down’s Syndrome placed for adoption by Barnardo’s North East (Mason, Hughes and Selman, 1998). The children are now aged 12 to 16 years and this article focuses on new issues arising for the children and their families, including the onset of puberty and the dilemmas over what to tell the children about their adoption. Overall the placements continue to prove successful with no breakdowns and a majority of the adoptive parents have subsequently adopted at least one more child with Down’s Syndrome.

**Background**

With the growing influence of permanency planning ideology on child care services in Britain in the 1970s, several independent projects were established which demonstrated that substitute families could be found for every child with any kind of disability (Argent, 1996, 1998). One such project was the New Families Project, which was developed in 1979 from the fostering and adoption work of Barnardo’s at Newcastle upon Tyne. Initially, the project concentrated on placing children aged five to ten years with behavioural difficulties, but later this was extended to those with learning difficulties and adoption became an increasing feature of the work. The placement of children with Down’s Syndrome commenced in 1981.

None of the children was being raised as an only child, ie all were in households with other children present. There were six families who, since adopting the research child, had adopted a further child with Down’s Syndrome and four families who had adopted or fostered other special needs children. Two of the families who
had adopted additional children with Down’s Syndrome had experienced the death of one of them. Five of the ten families had birth children, either from the present marriage or from a previous marriage (Selman and Mason, 1999).

Parents’ perspective
All the parents reported a high level of satisfaction about having decided to adopt a child with Down’s Syndrome and none regretted this decision, a finding similar to that of other studies of adopted children with disabilities (Glidden, 1985, 1990; Lightburn and Pine, 1991; Macaskill, 1988). Asked what they had found most rewarding about the experience, most were at a loss where to begin, reflecting that over the years there had been so many positive aspects of their life together that they found it difficult to express fully in words the joy and pleasure they had experienced:

She is so special. She is such a lovely bairn and everybody loves her. She’s so nice.

It’s the little things. It’s just like the enjoyment he gets when he asks for something and you buy it. It is just the enjoyment you see he has got.

For some parents the child had made a major contribution to their family, bringing a whole new meaning to their lives:

It is so difficult to put it into words. He keeps things in perspective because he’s such a happy chap and he doesn’t have tantrums and that.

If we had not had her what would our lives have been? She is a very nice, pleasant lady. Very caring.

Other families felt that their birth children had also benefited from having an adopted sibling in the family:

It has probably been the best thing I have ever done. I mean he has meant so much. The other kids, he has given them all so much when they were younger and now they give it back. They all have loads of time for him.

Often it was the small, everyday, taken-for-granted things, difficult to bring to mind immediately in an interview, which had brought the most satisfaction.

Children’s perspective
Even where there were communication difficulties between the researcher and the children it was still possible to gain an impression of how well the children were integrated into their new families. All were extremely friendly, relaxed and welcoming and those interviewed proved very willing to answer the questions they were asked. Children and their parents seemed to get on well together and between the children there seemed to be genuinely warm feelings of affection (Byrne, 1988), even where there was also a degree of rivalry.

In one case two brothers shared a bedroom and at times there were disagreements between them, but some of these were seen as a consequence of the seven-year age difference. In another family there was apparent sibling rivalry, with the research child taking great delight in ‘winding up’ his younger sister who took equal delight in crying and getting him into trouble with their parents, who told us that they generally left the two to sort things out for themselves without any interference. Sibling relationships in the families are discussed in more detail elsewhere (Selman and Mason, 1999).

Children and parents were seen to display delight and mutual respect for each other; the children were polite and well behaved and seemed to enjoy pleasing their parents. One girl took great pride in explaining how she was her mother’s helper and related several examples: tidying up her toys, making beds, washing and drying dishes (a prompted reminder from her younger sister) and putting her computer away. Another girl enjoyed helping her dad with the cooking and making biscuits with her mum.

The children appeared very sociable with a wide range of ‘favourite people’ including both adults and other children. Teachers at school or Sunday school, neighbours and relatives were named as
the adults they ‘liked best’ and all were able to give a long list of their ‘best friends’.

**Changing problems and difficulties**

As the children grow older the areas of concern for the parents have been changing. In their report on Stage 1 of the project Byrne and Flanagan (1987) noted as typical problems faced by parents such issues as extra work, additional responsibility, the wilfulness of the child, the influx of professionals and their own worries about the child’s health. By the time of the second report (Beesley et al, 1990) many of these difficulties had receded, but wilfulness was still an issue and a new range of practical difficulties to do with the child’s communication, general slowness in development and mobility had taken their place. Eight years later concerns had shifted yet again as we show below.

**Health**

Of the ten families only one reported no health problems; the remaining children had a variety of ailments ranging from the potentially serious to minor. For six of the children only one illness was reported with the rest having between two to four different health problems. At the beginning of each discussion about health most of the families said their children were healthy, a pattern noted by Carr (1995) in her study of non-adopted Down’s children, but further into the interview it often became apparent that the children in fact had a series of health problems. The only parents who immediately pointed out a serious health problem in their adopted child – the loss of sight in one eye – were equally quick to say that ‘he hasn’t got any health problems at all to do with Down’s’. Indeed, only one family attributed any health problems to the child having Down’s Syndrome: this was with reference to a ‘typical glue ear for a Down’s Syndrome’. All the other families were keen to point out that any health problems were no different to those any other child or teenager might experience.

Three of the children had asthma, but for only one was this causing serious problems – her parents reported that their daughter became very scared when she had an attack. One of the other girls was not able to give herself her Ventolin but otherwise seemed not to be bothered and coped well with the asthma. Two of the boys wore hearing aids, one needing his all the time, although he did not like wearing it and so removed it at every opportunity. The other, who only needed his aid in a classroom situation, also wore glasses in school. Other reported health problems included excema, wheat intolerance, skin sensitivity, ‘blocked oral glands’ and one child who had curvature of the spine.

Most parents indicated an improvement in the general health of the children since the previous stage of the research eight years ago. It was only in the one case of the child’s damaged eye that there had been any deterioration in health. As in the last report the parents showed confidence in their ability to cope with any health difficulties and in the majority of cases health was not considered a problem.

**Communication**

In 1990, when the children were aged between four and eight years, four families reported that poor communication/speech was a problem. In 1997, when they were aged between 12 and 16 years, the researcher met and spoke with all but one of the children. There was one child (aged 13) who had no verbal communication and one (aged 16) whose parents said he had very little speech. The mother of the 16-year-old, who was not present at the interview, reported that he had very good speech. The parents of the child with no speech were aware that he would never acquire the ability to speak but insisted he was nevertheless able to communicate his needs. The mother was actually concerned that her ability to understand his needs at all times might have been a handicap and hindered his need to speak. She seemed able to accept her son’s lack of speech, but her husband had not found it so easy and explained that it was not his son’s everyday needs but his emotional needs that concerned him.
Their son was able to express anger by banging things with his fist but other deeper feelings were not so easily expressed. Both felt sad that they were unable to share and discuss with their son simple things like what he had been doing at school each day.

The young boy with very little speech had similar problems. At school he was often asked what he had been doing at the weekend and was unable to tell. To try to get around this his parents had devised a method whereby they kept a book with simple drawings, each representing his most common activities. Therefore, when their son went to school on Mondays he only had to find the appropriate page and point for the teacher to know where he had been and what he had been doing. The school has found this a useful resource and is preparing a similar booklet for his younger sister who also has very limited speech.

More than one set of parents pointed out that even where their child did not have good verbal skills they were able to understand everything that was being said to them and in all cases poor verbal communication was only a problem on occasions. In all cases, with patience from parents and children, the latter were able to communicate their needs in one way or another.

**Behaviour**

All of the parents were quick to assert that their children were well behaved and that any problems they might have were quite normal for their age group. None reported problems with routine like getting up in the mornings or going to bed, but several readily admitted that the children could be wilful and stubborn, ‘answer back’, and at times ‘push us to our limit’. The parents who had described their children as particularly wilful in the previous stage of the research told us that they were now growing out of it (Carr, 1995):

*As she has grown older she has generally matured altogether. She used to be strong minded and extremely active. It is getting much, much better and she is sensible and her nature is quietening as she is getting older.*

In other cases children were more able to explain why they were being stubborn and what it was they were frustrated about:

*When she is being stubborn I usually try to find out why . . . because often I am not getting the whole picture. There is often a logical explanation for her stubbornness.*

The parents of two of the 16-year-old boys said that at times they exhibited quite aggressive behaviour. One suggested it was all part of growing up and that other children of 16 would understand more about their feelings; even though they may get annoyed they would be able to keep their aggression under control whereas their son was not able to do that. Even at his most aggressive, he was always sorry and shocked after he had lost his temper and would be very upset by his own behaviour.

For the second family their son’s aggressive behaviour was possibly more problematic because for the mother there was no real problem whereas the father found the aggression unacceptable. The mother’s explanation for their son’s violent outbursts was that they were an exaggerated but acceptable response to quite exceptional circumstances and events in his life.

In both cases the parents, although manifestly concerned about the behaviour, had been very supportive and loyal towards their children so that the behaviour was not likely to cause a disruption of the adoption. It was also clear that the aggression described was only a very small part of their overall behaviour; from day to day both were usually pleasant, amenable young men who were well integrated into their families, causing them no real problems.

**Protectiveness**

Generally the parents seemed very protective towards their children and, at an age when many youngsters would be playing in the street or calling for friends, most of the research children were not allowed out by themselves. A similar
pattern was noted by Carr (1995) who reports that the birth parents of children with Downs Syndrome tended to be uncertain, over restrictive and worried about even leaving their children alone in the house for short periods.

There seemed to be three main areas of concern which inhibited the parents from allowing their children much freedom. The first was a general feeling that the ‘world out there’ was a dangerous place:

I would have to know where they were because in this day and age people are just picking kids up off the street and taking them away, and it does frighten me.

Secondly, there was a feeling that by their very nature children with Down’s Syndrome were friendly and more likely to go off with strangers:

It is because there are too many dangerous people around. You can tell them a million times ‘don’t go with strangers’ but they love people. They would go if somebody was pleasant to them.

She is easily distracted if something catches her eye. She is a great one for adventures, so if someone said, ‘come on to the park’, she would follow them, no bother, absolutely no bother at all. I know that.

A third reason was concern about their children being able to find their way home, even if they had only wandered a short distance

However, three families had allowed their children far more freedom:

I can’t chain her in. It would make her miserable. She has got to live her life. I hope nothing happens.

He plays out on his bike with friends around the estate all the time and goes to Scouts, the shops, etc – he has no main roads to go on because there is an underpass.

He goes around to the local shop, which is across two main roads. I mean I pick the times when he goes. He will not go between four and seven o’clock when the roads are really busy. Sometimes he goes at half past three because I know there is a lollipop lady and she will put him across and bring him back. Or he goes on a Saturday morning.

Each of these families was concerned about the safety of their children, as clearly indicated by the above quotes, but unlike the other parents they had felt able to allow the children far more freedom.

**Background help and support**

Families raising children with disabilities will need more support than families without disabilities. This may come in the form of moral support or practical help with everyday activities and can be provided by statutory agencies, voluntary bodies or family, friends and neighbours.

**Family, friends and neighbours**

Over the years there had been support from grandparents (Byrne, 1988) but this had diminished through death and infirmity. However, the four families with older birth children continued to find them very supportive – a feature noted by Macaskill (1988) in other families with adopted special needs children – and willing to babysit any time. Many parents also reported that their friends and neighbours had been a source of support, taking the children out for the day and welcoming them into their houses.

**Respite care**

All families in the project saw respite care as a valuable resource, but use of such services differed between them, from one that only used a babysitter service some evenings to others that took full advantage of the whole range of schemes, from weekend and week-long breaks to school holiday play schemes. Four had never used such services including one family who felt they would have to be a ‘failing family’ to get support – a barrier identified also by Macaskill (1988) in her study of special needs adoption. Even the parents using a
'babysitting' service once a week were concerned to stress that they had never felt the need 'to be rid' of their children, but just wanted a few hours for themselves.

The needs of families change over time (Macaskill, 1988). One family who had never used respite care services were considering doing so to give the children an opportunity to become more independent as they grew older; another who had used respite care regularly for many years had decided they no longer felt the need for a break from their children.

Other families who had never used respite care had lifestyles that accommodated breaks with the children – one having their own caravan, the other being actively involved in youth club activities in which their son could be fully integrated.

Organisations
Eight years ago, at Stage 2 of the study, a majority of the families were members of the Down’s Syndrome Children Association but at this stage only one family were still members and they did not attend any of the social events, continuing their membership in order to keep in touch with issues about children with Down’s. One family had found social services able to offer practical help to them over the years and this was very much appreciated.

New Families Project
Contact with the New Families Project had decreased considerably since the last stage of the research when eleven of the 12 families were still in touch with the project. By 1997, none of the families maintained regular contact but all commented that they would not hesitate to turn to them for advice and support if the need ever arose. Both the project and the project workers were held in high regard and several of the families have continued close friendships with the social worker who placed their children.

Education
A major area of discontent was parents wanting their children to attend or have more time in a mainstream school, but there was also concern about the standard of education being offered in special schools, the balance between teaching social skills and academic subjects and whether the children should follow the National Curriculum.

Five families voiced discontent about the lack of opportunity to be educated in mainstream schools and three of these had taken on the local education authorities to fight for the education they wanted – in one case just a few more hours a week in a local school. Two families had sons who were educated in a mainstream school up until the age of about eleven years when they had to transfer to a special needs school.

The other parents have been quite happy to send their children to designated schools for children with special needs, with one mother sending her daughter to a special school despite being offered a place in the local infant school. These parents had felt the child would be unable to reach standards expected of them in mainstream schooling and that in designated schools teachers would have had training and experience in dealing with children with special educational needs. Some parents felt that special schools placed too much emphasis on meeting the criteria of the National Curriculum, while others thought it was better for their children to be covering similar topics to those taught in mainstream schools.

Sexual development
In the last report, one of the anticipated areas of interest was the sexual development of the children and the ways in which both they and their parents would manage such issues. We were concerned to find out what sex education the children had been given, how much of this they had understood and how the parents felt about future intimate relationships the children might have as they reach adulthood.

Sex education
All the parents acknowledged that there was a need for sex education but several expressed concern about how this should
be done and, as suggested by Van Dyke, McBren and Mathers (1996), there may be a need for individualised instruction and support. Some felt that the language used to describe reproduction and intimate relationships during sex education lessons in school was often inappropriate and in many cases there were doubts as to whether their sons or daughters really understood what they were being told. One mother spoke of her son coming home from school after having had a sex education lesson under the impression that, because he was a boy and his mother was a girl and they lived in the same house, ‘I can have sex with you’. His mother was initially horrified, especially as there were two older sisters living in the household, and she had to set about repairing the damage to make sure he understood more clearly who it was and was not appropriate to have sex with.

A couple of the children had a special boyfriend or girlfriend, with one of the girls giving her boyfriend a kiss on the school bus on the way home. Her parents were quite happy with this because it was a natural part of adolescence but, at the same time they did feel they had to be aware of possible dangers when the three siblings with Down’s Syndrome all started kissing each other:

She is very aware about falling in love and getting married. So kissing is becoming a thing – you have to watch and separate the three of them because they get in these embraces. They are play acting but they may not know the difference.

Some parents had been preparing their children from a very early age about the need to know the difference between appropriate and inappropriate touching because they felt it might take a long time for them to understand this:

From being able to hold the sponge she has washed herself. It takes a long time to get things through to her to really understand. I told her nobody touches her there and if anybody touches her she must tell mam. I mean apart from that you cannot do much.

Future relationships/partners
All parents were quite optimistic that their children would, in the future, be able to have an intimate relationship with a partner. They very much wanted their children to grow up to lead a life which was as normal as any other person’s and this included the possibility of marriage:

I don’t want him to be on his own for the rest of his life. I want him to be in a stable relationship and have all the experiences and the joys and upsets of married life, and if he can have family have a family.

However, not all parents were so positive and several expressed levels of concern about how their children would cope and be able to maintain relationships (Carr, 1995). Four of the parents were worried about whether their children would be able to understand the magnitude of maintaining or entering into a full-time relationship.

One couple were quite sure they did not want their daughter to have any children, even though they would love her to have a special partner of her own. This was partly because they felt she would not be able to take on the responsibility of a husband and a child. They were also concerned that by the time their daughter was of an age to get married and have children they themselves would be too old to offer much help.

Overall the parents had very positive attitudes towards their children’s sexual development and had approached it in their usual pragmatic fashion, dealing with issues as they had arisen and not living life anticipating the worst. However, there was a feeling that, if their children did enter into a relationship, it might well be at an older age than average owing to their generally delayed development.

Knowledge of adoption
An issue which may become more significant as the children reach adolescence and move into adulthood is their knowledge of adoption.
Adolescence is often a period of confusion, involving a search for identity and a development of self, which can be heightened for an adopted person. Because of their disability this process may be delayed for the young people in this research, but this does not mean it will not become an issue in the future. We therefore wanted to know whether the research children knew they were adopted. Did they understand that they had a birth family? Did the parents think their children would want to trace their birth family when they got older?

Asked whether their children knew they were adopted, five said they knew and five said they did not. A typical reason for not telling their child they were adopted was:

*We didn’t feel it was appropriate. It would be very confusing. There may be a time in the future when it is appropriate, but I don’t think so.*

One couple said they were leaving it up to the child to raise the topic of adoption, commenting that ‘if he wanted to know we would tell him but it hasn’t ever come up’. Another family had information to pass onto their son about his birth parents when they felt the time was right, but were quite sure he would never be able to understand the concept of adoption. In both cases the parents seemed ambivalent, hoping that the subject would not ‘come up’. There must be some doubt as to how their children will ever learn about their adoption – an area worth exploring further in the next stage of the research, when the children have become young adults with a right of access to their original birth records.

Other parents had been very open with their children and explained, as best they could, about the child’s family of origin. One family had a life story book for their daughter with photographs of her as a baby, which could help her to broach the subject of adoption in her own way when she is ready. However, even among the families who had tried to talk to their children about adoption, there were some reservations about how much they understood:

*. . . I don’t think it means anything to him. If they were to turn up tomorrow and you said ‘This is your real mother’, I don’t think he would be able to understand.*

When we have talked to her about being born to someone else it’s an irrelevancy. I am not saying it might not be an irrelevancy in 20 years time. I don’t know if it will ever be that important. I would hazard a guess that it won’t. It certainly hasn’t been up to now.

Macaskill (1988) reports a similar reluctance to initiate discussion about adoption in the families with disabled children she investigated: only three out of 17 parents had made any attempt to talk to their children – aged between six and 19 – about adoption.

**Conclusion**

This stage of the research supports the findings of Stages 1 and 2 in suggesting that the parents have surprisingly few areas of difficulty. All the children were described as being in good health but if there are any health problems the parents are confident in their abilities to cope. Difficulties related to behaviour were described as typical teenage problems which the parents expected them to grow out of. There was no major concern over their slow development and all had been delighted in their children’s progress, were proud of their abilities and expected continued progress for the next few years. Communication was not seen as an insurmountable problem and all parents found they were able to communicate with their children, even if their speech was poor.

What is clear is the parents’ ability to accept as natural and unproblematic most aspects of bringing up a child with Down’s Syndrome. They have grown in confidence and display a pragmatic approach to life, which seems to enable them to cope with any difficulties they are faced with.

One area that may prove to be more problematic as the children move through adolescence into adulthood is protectiveness. For a variety of reasons
the majority are currently hesitant about allowing their children to go out alone. They are unsure about their child’s competence to cope alone in the ‘outside world’ which they, the parents, feel is a dangerous place. Despite such concerns all the parents were optimistic about the future and hoped for a greater degree of independence for their children within a protective environment.

The main focus of the research has been concerned with experiences that are common to all parents of children with Down’s Syndrome (Beresford, 1994; Carr, 1995) rather than just those who have been adopted. The only aspect that was specifically concerned with the adoptive status of the children was whether they did or did not know they were adopted. Knowledge and understanding of their adoptive status is an issue which may become more important as the children reach adulthood, enter further education or the work place, or form relationships of their own. While they are still ‘children’ in the confines of their family adoption may not seem an issue to be discussed, but there is no guarantee this will be the case in the future.

This is one area that will merit more detailed scrutiny in the fourth and final stage of the study, when the children will have reached early adulthood. Other areas that will be examined in more detail include sibling relationships (Selman and Mason, 1999) and the strengths and characteristics of the adoptive families which have contributed to the success of these placements.

Overall the findings of Stage 3 of the study indicate that the adoption of the children with Down’s Syndrome has proved to be a rewarding and positive experience for these ten families, none of whom had any regrets about their decision to adopt, giving a clear indication that such adoptions can and should be continued with confidence.

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