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Relinquishment for adoption of babies with Down's Syndrome: announcement of the diagnosis to parents and institutional practices of maternity staff

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Abstract :

This article is a synthesis of research findings based on a study conducted in France between 1990 and 1996. The project aimed to establish a clearer understanding of why Down's Syndrome infants were given up for adoption, to evaluate the extent of the phenomenon and its evolution over the long term. It also analysed the impact of the diagnosis on the parental decision whether to keep the baby or not and highlighted the determining factors in babies being given up for adoption.

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The adoptive child's profile has been changing for the last twenty years with the lower availability of healthy infants for adoption and the increase in adoptions of children with special needs who are older or from abroad. In France, according to the relevant law of June 6, 1984, any Ward of the State can be considered for adoption. In the 1990s, each year about 3-4 babies per thousand were placed for adoption in Paris. More than 15 years ago, social workers noticed that a significant number of Down's Syndrome, infants were given up yearly for adoption. They accounted for about 10% of infants placed for adoption. Down's syndrome, which can be rapidly diagnosed, is the main disability which results in parents giving up a baby at birth (Dumaret and Rosset, 1993).

Most previous published work on Down's children has been about experience in biological and adoptive families. This article reviews the phenomenon of relinquishment (Byrne et al. 1988, Carr, 1995, Mason et al. 1999, Sloper et al. 1991).

Backgrounds

Previous research has documented parental shock and distress after been given the diagnosis of Down Syndrome (Quine and Pahl, 1987) and shown the psychological adaptability parents had to display if were to respond positively (Gath, 1985). Other studies have explored the point of view of medical teams and their distress when faced with the relations of parents, the functioning of maternity wards and the consequences for the parent-child relationship and bonding (Richard, 1986). As a result, a considerable body of work exists on how parents are informed about the disability but there is no reported data on the links between the disability and the choice about keeping the child or relinquishing for adoption.

The parental reaction to the birth is, to a large extent, determined by the negative social representations associated with Down's Syndrome. A study carried out in the early 1990's by the *Institut National de la Santé et de la Recherche Médicale* showed that a large majority of people were in favour of abortion with babies with Down's Syndrome (73%). The authors refer to the

considerable influence of both the cultural milieu and religious beliefs (Julian-Reynier et al., 1993). Opinion polls among doctors and women show that the majority are in favour of abortion when Down's Syndrome is diagnosed.

Formerly, the medical staff tended to be pessimistic in their prognosis regarding the future social integration of children with Down's Syndrome. Some studies even documented cases of infanticide (Shepperdson, 1983), while others indicated that institutionalisation was proposed to the parents in 6-8 percent of cases (Lucas and Lucas 1980). Both communication of the diagnosis and support from medical teams and social workers have improved (Cunningham et al., 1984), while French ministerial guidelines for maternity staff were issued in 1985.

This article reports on a research program focused on the relinquishment of Down's Syndrome children. Firstly, we investigated the extent of this phenomenon in Paris, secondly, we examined the impact of the diagnosis disclosure in maternity wards and the risk factors associated with placement for adoption.

Down's Syndrome infants placed for adoption

An exhaustive census of Down's Syndrome babies born between 1980-89 in Paris and given up for adoption was undertaken (Dumaret et al., 1996a). Permission for the research was given by the appropriate Local Authorities and the State Wards Family Council in Paris. Private adoption agencies also contributed to the study. For ethical reasons linked to the request for anonymity concerning the relinquishment and adoption of infants (in full adoption cases), our study on family characteristics and those of the children was based on file data only.

One hundred and two babies with Down's Syndrome were released for adoption over a ten-year period. They were born to couples receiving medical supervision and were wanted pregnancies. Four out of ten families had already had one or more children. Most mothers (n=92) were under aged 35. The majority had not had antenatal screening. The families that gave up their child mainly

belonged to middle and upper classes.

Almost half of the babies (43%) had been adopted several months after relinquishment. A similar proportion was living within foster families. Very few were living full-time in a institution residential. Eight percent had been resumed their place in their biological family and 6% had died before the age of six months (from heart complications). Placement in adoptive families by private adoption agencies was faster than placement by the Local Authorities, since private agencies operate as a large network throughout France.

Three-quarters of foster carers were working class or white collar workers while more than two-third of the adoptive families had upper-middle and upper socio-economic status. Families adopting children with Down's Syndrome had a specific profile. Most already had biological children (2/3). Also their family size was large (with an average of 4.3 children per family compared with 1.7 for the typical French family). According to the founder of the most prominent charitable organisation for the adoption of Down' Syndrome children (Emmanuel), half adopted two Down's Syndrome children because: "they look very much alike, they have the same plays and same worries" (six in ten families, cf. Selman and Mason 1999, p243).

It appears to be quite common for adoptive families to have a mix of birth children and adoptive ones, the latter having developmental disabilities and/or coming from foreign countries. (Glidden 1991, Mason et al. 1999)

Communication of the diagnosis and its implications

The diagnosis and its communication at birth are likely to affect the development of parent-child bonding; some parents are unable to face the truth, even with the support and backing of the medical team. Parents will be affected by their assumptions about the disability itself, with its negative social representations, and also by the manner in which doctors provide information and offer support.

The second stage of the research program focused on institutional practices concerning communication about the diagnosis in Paris maternity wards. Semi-structured interviews were conducted with the medical teams and tape-recorded (Dumaret et al., 1996b). The goal was to investigate the staff representations of the disability, the conditions under which the diagnosis was given to the parents and the options they could choose: returning home with the infant, temporary care in a state-run nursery or placement for adoption; this third option has been proposed in nurseries since 1985. Seven state-run and six private maternity wards took part in the study. They accounted for 60% of the babies with Down's Syndrome relinquished for adoption between 1980 and 1989. It was also possible to investigate staff views on the parent-child bonding process in four of the state-run nurseries.

Timing practices varied greatly in the two contexts. In maternity wards, mothers had to leave within three days. Staff found it hard to deal with parents' strong emotions after learning the diagnosis. In state-run nurseries, babies were temporarily cared from birth to up to several months. They received a lot of attention and care, the staff took the parents' dilemmas into consideration and they were supported in their decision.

The interviews with the medical teams revealed two striking attitudes. Some expressed dismissive articles: *"This shouldn't happen nowadays"; "attitudes to of Down's Syndrome are still horrible"*, but some staff expressed sympathy: *"It's true, you don't really feel sorry for the baby, it's the parents who really suffer"*.

A quarter of the maternity wards responded negatively to a baby who was not the "perfect child"; In such places relinquishment rate was high: *"This baby is abnormal, it's a medical failure"; "this shouldn't happen any more";* Paediatricians emphasised the fact that both parents and professional staff were not ready for a disabled child's birth, *"The medical training is too computerised, too technical"*.

The announcement of the diagnosis was always made by the paediatrician, sometimes together

with the midwife or the obstetrician. More than half the maternity wards (8/13) gave the diagnosis to both parents in the presence of the infant ; in these cases there were fewer relinquishments than when the announcement was made to both parents without the infant or to a single parent (on average: 2.8 vs 7.8 relinquishments in 1980-90). The vast majority of maternity wards (9/13) made an announcement very quickly, which minimised the staff's ability to cope with distress. After noting the disastrous effects of making a sudden statement in the delivery room, some professionals thought that they had rather wait before informing the parents, especially when there was any doubt concerning the diagnosis. This did not eliminate the risks of the baby being abandoned ultimately. Transfer of babies with Down's Syndrome to another institution was sometimes a means for the maternity personnel to avoid the issue of telling parents the diagnosis. The survey revealed that five of these maternity wards separated the child from mother at birth : the average number of relinquishments was obviously higher in these places than in the other maternity wards (7.8 vs 2.7).

As far as various care solutions were concerned, most of the maternity staff suggested to the parents that they would go back home with their baby. All mentioned the possibility of a temporary placement in a childcare centre to give the parents time to find out more and reflect over a longer period. All but two maternity teams also suggested the possibility of giving up the child and in a third of the cases adoption was proposed as the first solution for care (4/13).

The staff in five maternity wards took particular care about how best to communicate the diagnosis and offer supporting quickly the parents. Few babies were relinquished in these places. By contrast in some maternity wards, the high rate of babies released for adoption reflected the lack of specific personnel to deal with such events, a high staff turnover rate and above all a lack of training.

Risk factors for placement

The final stage of our research involved the follow-up of babies with Down's Syndrome born in two regions of France where congenital birth defect registries are available. Approval for the research was obtained from the *Commission Nationale Informatique et Libertés*. A retrospective cohort of 593 babies with Down's Syndrome was identified, comprising 407 infants born between 1980 and 1990 in the Paris region and 186 infants born between 1984 and 1990 in the Bouches-du-Rhône region of Southern France around Marseilles (Dumaret et al., 1998).

Over the whole period, one in five babies with Down's Syndrome were relinquished at birth for adoption (19.4%). This rate was much higher in Paris (22.6%) than in the Bouches-du-Rhône (12.4%). However, the abandonment rate grew faster in this region, from 4% in 1984 to 19.2% in 1990, while the already high figure for Paris increased more slowly. The status of the maternity units (public/private) and their size had no effect on the rate of babies being put up for adoption. Multivariate analyses indicated that a high rate of infants with

Down's Syndrome placed for adoption was linked to:

- national origins of the mothers: French more than other mothers
- place of residence: more relinquishments among mothers from suburban areas
- birth rank: first-borns more than the others
- maternal age: higher rates for mothers between 25-34 years of age
- presence of associated congenital birth defects: parents found it particularly difficult to face a combination of mental disability and medical complications.

In both the regions studied, Paris and the Bouches-du-Rhône, only half of the relinquished babies were eventually adopted (58/115).

Three-quarters of the 115 infants relinquished in the Paris and Marseilles areas were born to mothers whose identity was known in the maternity wards but the births were registered retrospectively as being "anonymous delivery": (*accouchement sous X)*, so that identity of the

mother was not recorded. This was not in accord with the law, but according to the Local Authorities was done for administrative convenience. As a result, the Down's Syndrome child will not be able to discover his/her origins.

Especially for foreign readers, it is necessary to point out that France is one of the very few nations in the world with a policy that allows for anonymous delivery. The institutional procedures for relinquishing an infant for adoption are shown in Table 1. There are two types of admission in a maternity ward. In most cases, the women give their identity at admission. Others opt for "anonymous delivery": they demand secrecy regarding their identity since they have already scheduled to relinquish the baby for adoption. This group number around 600 cases per year. Although the mothers do not give personal details, they can leave some information pertaining to the current situation, or their health status, and they can choose a name for the child. This results in a written document jointly prepared with a social worker. Nobody may oblige them to reveal the truth about their identity, but they are free to choose themselves to go back to the Local Authorities months or years later to provide further information, so that, once adult, the child may trace his birth family. This procedure has long been hidden by social workers and agencies because of the French custom of full adoption whereby disruption with biological parents is regarded as irreversible. France has also another type of adoption i.e. simple adoption. It is frequently chosen for intrafamily adoption and for long term foster carers who have been raising a child whose parent has a severe mental illness and cannot sign their consent for adoption. In such cases the adoptive parents are only legal guardians but the adopted child is still linked with his/her biological family.

All births must be registered at the Town Hall of the birthplace within 3 days following delivery. Married parents simply declare the birth since the child automatically has a legitimate parentage through marriage. Unmarried couples have not only to declare the birth but also to recognise the child to establish the legitimacy (parentage). Infants born through anonymous delivery have a legal

guardian (the State) but no parentage. (Table 1).

Secrecy about the mother's or parents' identity may be requested by parents whose child has a legal status when signing the adoption consent by parents, but secrecy is automatic with anonymous delivery. Three first names are given to the infant, whose identity will change once adopted. Then, he/she will acquire a parentage through his/her adoptive family. In these cases of secrecy, the child will have no information on his/her biological parents. However, sociological investigations concerning women who choose anonymous delivery have shown, for about the last decade, an increase in amount of data in the files. With the UN Convention on the Rights of the Child (1989), an important social trend in favour of the search for origins has been spreading. Very recently, the French Government has decided to create an independent State Organisation so that biological mothers who had anonymous delivery can provide information relevant to their identity.

Discussion and subsequent developments

The available results indicate that socio-cultural context and attitudes have a major impact on parental decision-making, demonstrated by the over-representation of middle and upper SES families among the parents who relinquish the baby for adoption. How the diagnosis is communicated may soften the tendency for fears about the disability to lead to the child's abandonment, especially when parents have not made up their minds.

There is little data available in Europe with respect to this situation. The proportion of Down's Syndrome children living in families or institutionalised is not accurately known. Making comparisons is difficult because of the different ages of children included in analysis. In the United Kingdom, 8-10 per cent of Down's Syndrome children born between 1970-75 were relinquished at birth and later. 17% were not taken home from the maternity hospital in the study by Carr (1988), while at school age 7 - 8 per cent were not being raised by their family (Sloper et al., 1991). It

seems that a higher proportion of babies with Down's Syndrome are given up for adoption in France. Two factors to explain this are the short time frame for legal consent to adoption and the possibility of requesting secrecy. These can lead parents to make up their mind in haste. In the United Kingdom, according to the Adoption Act, 1976, consent is ineffective if given by the mother less than 6 weeks after the child's birth. Eight weeks in the equivalent period in Germany and a month in Spain. The option of legally sanctioned anonymity with regard to parental responsibility does not exist in these counties.

It is questionable whether it is right for the law permit of such a quick transfer of responsibility from parents to the Local Authorities. When there is a strong and perhaps conflicting emotional reaction, time is needed for careful consideration.

The role of health professionals is also crucial. When suggesting the option of adoption, do they really know that only half of the children placed for adoption will in fact be adopted? Relinquishment of an infant with a disability is a psychologically tough decision. Issues and options are complex. Our studies revealed that parents' decision-making occurred mainly while they were shocked upon learning the diagnosis. Also, there was little discussion during the brief stay in the maternity ward. In practice, the support network focused almost exclusively on families who decided to keep the baby while the other parents were left alone once they left the baby at the maternity unit or sign the legal documents for adoption.

For some parents, the emergency decisions may lead to major tensions and perhaps the couple separating. Family secrecy can also have pathogenic effects. The adopted child growing into an adult has limited knowledge of her history. For proper decisions to be made and the ill-effects to be minimised parents should be given all the time they need to think thoroughly and learn about the available solutions. To do this, an open relationship need to be established with the professionals involved to ensure each individual is treated with the respect he/she deserves.

The conclusions from the research were used to modify practices in the middle and late 1990s.

The research results were widely published in maternity wards. Training was provided for social work teams in Local Authorities. As a result, there was an improvement in legal adoption judicial procedures and in the processes for revealing the diagnosis. Our follow up data shows that the proportion of babies with Down's Syndrome among relinquished babies for adoption in Paris dropped from 10% between 1980 and 1989 to 6% in 1995-96 and to 4% in 1998-99. Several recent scientific papers show that improvement and systematic widespread use of biological antenatal screening have resulted in an increase of the number of termination of pregnancies (References?)

Despite the fact that social attitudes to people with a disability are improving, sadly the general population still tends to react negatively to people with Down's Syndrome. Changes are needed outside hospitals as well as within.

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Table 1 : Institutional procedures, parentage and time period for revoking the adoption order

Admission in maternity ward	**Legal proceedings** Code de la Famille et de l'Action Sociale	**Child parentage (legal status)**	**time period for revoking the adoption order**
The woman gives birth under her own name			
1. married parents	After declaration to the birth register; the baby is relinquished for adoption at the hospital. Consent may be signed by both parents or one parent.	*Legitimate parentage (through marriage)* When the parent(s) sign(s) consent to adoption, secrecy of their identity may be asked or not	the child is free for adoption after: 2 months (if both parents signs) or 1 year (if one parent signs)
2. unmarried parents	Declaration to the birth register may be made with or without recognising the infant: Baby given up to adoption at the hospital.	*Parentage established* Secrecy of parentage may be asked *No legitimacy = no parentage* Part of the birth's parent identity unknown	2 months or 1 year
The identity of the woman is secret *anonymous delivery*	Decided before birth or when entering hospital : Birth registration by the State Officer (3 first names) Baby left in hospital	No legitimacy, but the mother may later recognise her child on the birth register if not adopted. Parentage is then established	2 months