

Adoption and fostering of babies with Down syndrome: a cohort of 593 cases

Annick-Camille Dumaret ^{1*}, Catherine De Vigan ^{2,3}, Claire Julian-Reynier ⁴, Janine Goujard ^{2,3}, Dominique Rosset ⁵, Ségolène Aymé ⁶

¹ CERMES, Centre de recherche Médecine, Science, Santé et Société CNRS : URA0934 , INSERM : U304 , 182 Boulevard de la Villette, 75019 Paris,FR

² Recherches épidémiologiques en santé périnatale et santé des femmes INSERM : U149 , INSERM : IFR69 , Université Pierre et Marie Curie - Paris VI , Centre de Recherche Inserm 16, Avenue Paul Vaillant-Couturier 94807 VILLEJUIF CEDEX,FR

³ Registre des Malformations Congénitales de Paris Registre des Malformations Congénitales de Paris , Villejuif,FR

⁴ Epidémiologie et Sciences Sociales Appliquées à l'Innovation Médicale INSERM : U379 , Université de la Méditerranée - Aix-Marseille II , Institut Paoli-Calmettes 232, Boulevard Sainte Marguerite 13273 Marseille Cedex 09,FR

⁵ DASES, Aide sociale à l'enfance de Paris Aide sociale à l'enfance de Paris , Paris,FR

⁶ Cartographie du Genome Humain a des Fins de Recherche Clinique INSERM : SC11 , Université Pierre et Marie Curie - Paris VI , Hopital Broussais PARIS VI 102, Rue Didot 75014 PARIS,FR

* Correspondence should be addressed to: Annick-Camille Dumaret <dumaret@vjf.cnrs.fr >

Abstract Summary

Recently, professionals in France have noticed an increase in newborns with Down syndrome being placed up for adoption. The aim of this study was to investigate DS babies given up at birth for adoption and to consider the possible determinants of this situation in order to assess social acceptance of DS. A retrospective cohort of all living DS babies was constituted from two birth-defect registries (Paris: 1981–90, Marseilles area: 1984–90). Follow-up data was collected: characteristics of baby, birth parents and maternity units, age when given up for adoption and type of foster care. Results showed that 19.4% of infants with DS (115/593) were rejected by their parents. Multiple regression analysis indicated that foreign origin of the mother, area of residence, no associated major malformation, maternal age (15–24), and birth rank (>2) variables were significantly associated with a lower placement rate. Among the 115 abandoned infants with DS, 88 came from unknown parentage (76.5%). For half of them, adoptive placement (88/115) occurred before the age of six months. Socio-cultural attitudes play a great part in these family decisions. Equally, important is the manner in which professionals propose adoption as an alternative to these DS parents. They should be encouraged to consider all options before making a decision so that the best solution can be found for the interest of all.

MESH Keywords Adolescent ; Adoption ; Adult ; Cohort Studies ; Foster Home Care ; France ; Humans ; Infant, Newborn ; Maternal Age ; Occupations ; Retrospective Studies ; Social Class

Author Keywords Down syndrome ; human adoption ; foster care

INTRODUCTION

Until recently, babies were placed up for adoption by their biological parents mainly for psycho-social reasons. Only recently, professionals in France noticed that parents tend to give their newborn up for adoption on the basis of the diagnosis of disability at birth. This phenomenon has been documented in two French studies. The first survey conducted in Paris on all babies born between 1985 and 1987 who were put up at birth for adoption, showed that 12% had Down syndrome (DS). These babies represent 25.9% of total babies with DS (Dumaret and Rosset, 1993). The second survey, conducted in the Marseilles area between 1984 and 1990, revealed that 12% of the babies with DS were placed for adoption in the maternity unit (Julian-Reynier et al., 1995).

In the United Kingdom, studies show that 8–10% of infants with DS born between 1970–75 were abandoned at the maternity ward and, later, at pre-school and school age, 8–17% of DS children were not raised by their family (Carr, 1975 , 1988 , Gath, 1985 , Sloper et al., 1991). Recently, a follow-up study in two British regions reported a 7% adoption rate (Brookes and Alberman, 1996). In Israel, in 1986, it was noted that 40 % of babies with DS were abandoned in hospitals and 95 % of them died in the first year (Ben-Neria et al., 1986).

It was not possible to determine whether our findings were specific to France as no similar study exists. If such findings were specific to our country, they could be due, in part, to the French legislation, established in 1941 to protect illegitimate babies and the confidentiality of the mothers who relinquished them. For this reason, medical teams are accustomed to presenting adoption as an alternative at birth since it is a legally established option (Circulaire, 1985). The interest of health professionals in the findings of these French studies suggested the need for further investigations. These were immediately initiated in order to identify the likely determinants of the high rate of infants

with Down syndrome given up for adoption. A retrospective cohort of 614 babies with DS born in Paris and in the Marseilles area was constituted.

SUBJECTS AND METHOD

Definition of the cohort

The cohort consisted of all live children with DS born between 1981–1990 in Paris, and 1984–1990 in the Marseilles area. In both areas, a systematic birth-defect registry has been organised (EUROCAT registries n°5 and 22) (Lechat, 1992). The prevalence of DS observed in these registries when compared to single-year maternal age estimates (Halliday et al., 1995) can be considered exhaustive.

Data collection

Systematic information to the EUROCAT registries includes the child's birth date, gestational age, birth rank, description of birth defects, vital status and results of karyotype; characteristics of maternity unit; parents' place of residence, ages and occupations according to the International Classification of Occupations. Maternal ages were classified into five groups and birth rank into three groups. Associated malformations were considered only when surgical treatment was requested in the first year of life. Mothers' occupations were classified into three categories: a) managers, directors and independent professions, b) intermediate professions, craftsmen, workers, unskilled and semi-skilled workers and c) unemployed and homemakers. Maternal countries of origin were divided into two classes (France and foreign origin). Fathers' occupations and countries of origin were not used because much of these data was missing. Maternity units were classified according to their status (public, private) and their size (number of deliveries per year). The two registries have legal authorisation for anonymous statistical exploitation of data from the Commission Nationale de l'Informatique et des Libertés (CNIL).

Complementary data concerning possible placement for adoption, using sex and infant's date of birth for matching samples, were obtained from maternity units, regional registries of State Ward's Family Councils and three private agencies devoted to handling the adoption of handicapped children. For infants given up for adoption, data were available regarding time of relinquishment, parental confidentiality, child's age when placed in foster or adoptive families, and whether or not the parents revoked the adoption order.

Data analysis

Univariate statistical analyses (using chi-square tests) and multiple logistic regression analysis (forward procedure) were performed (SAS software), using the DS child placed up for adoption as the dependent variable. Variables introduced in the model were those that were significantly linked to the parental decision to give up the child in the univariate analysis at a 0.05 level. Several variables such as maternal age, occupation and birth rank had to be subdivided into dichotomic variables, each class being tested versus the others in the multivariate analysis. Odds ratios are given with their 95 percent confidence intervals (CI).

RESULTS

The study population included 614 babies with DS. The information on whether or not they were given up for adoption was known in 593 cases (96.6%), 407 from Paris and 186 from Marseilles. The proportion of infants with DS placed for adoption at the maternity units during the study period was 19.4% (115/593), significantly ($p < 0.005$) higher in Paris (22.6%) than in Marseilles (12.4%). Although no time trend was observed in Paris (Table I), a significant one was observed in Marseilles ($p < 0.02$), as already reported (Julian-Reynier et al., 1995). The two geographic areas also differ in some other aspects (Table II). The birth rank was lower for Parisian infants with DS. More DS births took place in large maternity units in Paris than in Marseilles. Data on survival were obtained for 577 children. Among them 43 (7.5%) died during the first week of life.

Factors linked to the decision to put the child up for adoption

Two groups were defined according to the parental decision regarding adoption. Comparison of the distribution of variables showed significant differences (Table III). There was a significant linear trend between the placement rate and birth rank: the lower the birth rank, the higher the placement rate. This rate was significantly linked to the distribution of maternal ages: the highest placement rate was observed for mothers aged 25–34. Mothers of the highest social class gave up DS babies significantly more often than those in lower social classes. Mothers' country of origin was also linked to the decision: parents from foreign countries chose to place their child for adoption less often than French parents.

Most of these variables were strongly linked. There was a significant link between maternal age and socio-economic status, maternal age and birth rank, between region and size of the maternity units, region and birth rank. The multivariate analysis for assessing the respective importance of these factors was performed on 425 cases for which all the studied variables were documented (Table IV).

Four classes of variables were found to be significantly associated with a lower placement rate: mother of foreign origin, residence in Marseilles area, maternal age (15–24) and birth rank (> 2). Awareness of a concomitant major malformation was significantly associated

with a high placement rate. Maternal occupation, which was significantly associated with giving up the child in the univariate analysis, disappears as an explanatory variable in the multivariate analysis.

Follow-up of the DS infants placed for adoption

Half of the 115 DS babies were adopted (58), half of them being adopted before the age of 6 months (Table V). Among these adoptions, 29 were arranged directly by a private agency and 27 were placed by a public agency where, with the collaboration of private agencies, adoptive families were found. Only two children were adopted through public agencies (ex-foster families). For 27 babies, the parents signed a formal consent to adoption without requesting anonymity (23.5%), 88 babies were declared to be from unknown parentage (76.5%), and among them, five mothers who knew DS diagnosis before the birth elected to deliver anonymously.

DISCUSSION

This study addressed the question of parental attitudes towards children born with Down syndrome, their determinants and the short-term consequences for the children. As the survey population is situated in regions where records are very likely to be complete, the results are very informative.

The data necessary for the analysis of the determinants of parental attitudes were not available for all cases, because data was retrospectively collected from several sources and because of confidentiality constraints. In general, the educational level and social class of the parents could not be properly evaluated, due to a lack of precise information. Estimates were based only on mothers' jobs, which were known in 84% of the cases. These jobs were classified into broad categories, which did not reflect the social reality. Maternal country of origin and birth rank of the DS infant were known for 88.2% and 83.5% of cases, respectively. There is no evidence to suggest that the cases with missing data are significantly different from others, but it cannot be proved that both are alike.

Several variables linked to the parental decision to place the child have been identified. The most influential variable is the mothers' country of origin. Women from North Africa, Asia, Black Africa and the Caribbean rarely chose to give up their disabled newborn. This could be explained, in part, by the fact that adoption does not exist in the Moslem religion, but seems to be mostly the effect of general cultural determinants. The second influential variable is region of birth: a higher proportion of DS infants were placed for adoption in Paris than in the Marseilles region, independently of the other variables. Paris is always slightly different from the rest of the country, especially in the use of new medical technology. For example, it has been noted that Parisian obstetricians are more often in favour of termination of a DS pregnancy than obstetricians in other regions (Julian et al., 1989 , Geller et al., 1993). The two other important variables identified were: birth rank and maternal age. The birth rank >2 could be explained by a motherhood more established through previous experience. Maternal age, with the highest rate of giving up the baby for adoption after 24 years-of-age, could be due to the fact that career women are less likely to accept a disabled child because of professional considerations and constraints.

DS infants with major malformations, mainly cardiac ones, are more often abandoned. The reasons are certainly very complex. Parents may feel that they are not able to cope with both the mental disability and the medical problem. They also may feel that natural selection should have occurred (a view often expressed during genetic counselling sessions), or a prenatal diagnosis of the cardiac defect should have been made.

All these determinants of parental attitudes need to be explored further to better understand their separate roles.

The univariate analysis showed a high rate of families belonging to high social classes (26.9%). This is in agreement with the more pessimistic perception of the development of the DS child in these social classes. Formerly, the future of the child was viewed in a negative way by the medical staff, and prognosis of social integration was lower among physicians than parents (Springer and Steele, 1980 , Berry et al., 1981 , Pueschel et al., 1986 , Murdoch and Anderson, 1990 ,). Now with the increase of prenatal screening as a standard of care, social acceptance of DS may be even more difficult. The acceptance of termination of pregnancy for DS by high social classes has been shown to be very high (Geller et al., 1993 , Renaud et al., 1993 , Julian-Reynier et al., 1993). The lower classes show a higher tolerance for severely handicapped children (Shepperdson, 1983).

This study reveals that adoption is frequently presented as an alternative to parents of DS newborns in France. The role of professionals in the determining parents' attitude must also be considered. In the past, professionals proposed institutionalisation as a solution for parents who did not wish to raise their DS infant. The placement option was recommended to parents in 6–8 % of cases (Pueschel and Murphy, 1976 , Emde and Brown, 1978 , Lucas and Lucas, 1980 , Elkins et al., 1985 , Murdoch, 1984 , Springer and Steel, 1980). These professional and parental attitudes changed in the middle seventies with the development of research on mental retardation and the establishment of adoption agencies for handicapped children. At the same time, there were improvements in recommendations about how to inform the parents of the DS diagnosis, and increased support from social workers and medical teams (Circulaire, 1985 ,

Cunningham, 1977, 1984, Pueschel, 1985, Gath and Gumley, 1984, Murdoch and Gurr, 1992, Gayton and Walker, 1974). It may be that the parents who chose in the past to institutionalise their children are now those who give them up for adoption. Due to a lack of adequate information, we are unable to say more about these changes. This represents a limitation of the study.

In France, when a child is delivered in a maternity unit, the parents or the guardian of the child must register the birth within three days after delivery at the Town Hall of the birth place. If the baby is given up for adoption, at birth or at any time later, the parents may revoke the adoption order within the next three months. The question of a possible link between the French adoption legislation and the observed high rate of children given up for adoption at birth (19.4%) should be explored in relation to the particularities of this law. There are two major differences between France and other European countries with respect to the relinquishment of children for adoption. One difference is the time frame for legal consent to adoption. In France, it may be decided at birth and the baby is left in the hospital. In the United Kingdom (Adoption Act 1976), consent for adoption is "ineffective if given by the mother less than six weeks after the child's birth". In Germany, the equivalent period is eight weeks and in Spain, one month. The other difference is that, in France, there is an option of requesting secrecy of parental responsibility (surname and birth place of parents are not mentioned on the birth certificate or the Register of Births). This occurs not only when women give birth in a maternity hospital under anonymous conditions, but also when they refuse parental responsibility (parentage is not legally established) or formally sign a consent to adopt. When the adoption is arranged, either by the Child Welfare Authorities or by an adoption agency, the secrecy of parentage is protected by law. The difference between the rate of children given up for adoption in the French cohort (19.4%), and that of the Manchester cohort (8–17%) or the Brooks and Alberman UK cohort (7%), may be due to discrepancies in the children's ages at the time of evaluation. However, due to the lack of precise data on the child-rearing environment in France before 1980, and on the DS infants' situation in other countries, comparison is difficult. Further studies are clearly needed to compare adoption rates over time and across countries.

When a DS child is born, professionals, as well as parents, are overwhelmed by the event. Telling the diagnosis to the parents is a crucial moment in the parental history (Gath, 1985, Carr and Oppé, 1971, Quine and Pahl, 1987). Generally, this initial information is not remembered, even if given in an empathic, sensitive manner. It takes a long time for parents to adjust to the reality of their disabled child (Richard, 1986). The decision to give up a child is made too often in haste at a time when the parents are in state of great emotional distress (Dumaret et al. 1996). Most likely because of a misunderstanding of the law regarding the parents' anonymity, medical and social staff may rush parents into making decisions. Anonymous delivery happens in rare cases in which the handicap is diagnosed prenatally and the parents decide, before the birth, to offer the child for adoption. In all other cases, the identity of the mother of the DS baby is known by the maternity unit. However, in our study the name was retroactively suppressed to simplify legal procedures in more than half of these cases (36). Proper application of the procedures allows parents the time to thoughtfully decide about the future of the child and their own confidentiality.

Our data show that a great majority of infants with DS were given up for adoption. The adoptions were arranged by private agencies which have a very large and active network throughout the whole country. Only half of these children were adopted, an additional 36% were reared in foster families and 14% were institutionalised. In total, 86% of the infants with DS will live with families, but it is possible that their future will be different after they reach legal voting age. We suspect that children in foster families run a greater risk of being institutionalised in adulthood, when their foster carers are no longer remunerated. This should merit further investigation.

The ultimate goal is to give parents the possibility to make a thoughtful decision. It seems unreasonable to expect parents to make the decision to a transfer of parental rights and duties to society shortly after delivery, during this period of confusion and pain. They should have accurate information regarding the prognosis of the child, alternatives for care, and appropriate medical and social services in the community. During the newborn period, parents must be encouraged and supported to take the necessary period of time, different for each couple, to independently choose the appropriate solution for infants and parents.

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Table I

Proportion of DS children given up for adoption at birth in Paris and Marseilles areas (1981–1990)

Year of birth	Paris area given up for adoption/total DS	%	Marseilles area given up for adoption/total DS	%	TOTAL % given up for adoption/total DS
1981	6/36	16.7			
1982	9/34	26.5			
1983	10/47	21.3			
1984	7/44	15.9	0/18	0.0	11.3
1985	12/44	27.3	1/25	4.0	18.8
1986	15/42	35.7	5/33	15.2	26.7
1987	10/36	27.8	3/26	11.5	21.0
1988	6/44	13.6	2/25	8.0	11.6
1989	10/47	21.3	7/33	21.2	21.3
1990	7/33	21.2	5/26	19.2	20.3
Total	92/407	22.6	23/186	12.4	19.4

Table II

Comparison between Paris and Marseilles areas for some characteristics of the study population

Characteristics	Paris area n=407	Marseilles area n=186	p value
sex (n = 592)			
male	193 (47.5%)	101 (54.3%)	ns
female	213 (52.5%)	85 (45.7%)	
birth rank (n = 495)			
1	149 (45,6%)	58 (34,5%)	
2	82 (25.1%)	59 (35,1%)	p<0.05
≥3	96 (29.4%)	51 (30,4%)	
major malformations (n = 590)	71 (17.6%)	67 (36.0%)	p<0.001
maternal age (n = 574)			
15–24 years	48 (12.2%)	24 (13.4%)	
25–29 years	80 (20.3%)	39 (21.8%)	
30–34 years	119 (30.1%)	46 (25.7%)	ns
35–39 years	112 (28.4%)	53 (29.6%)	
40–54 years	36 (9.1%)	17 (9.5%)	
mother's occupation (n = 497)			
homemaker, no occupational job	115 (33.3%)	54 (35.5%)	
intermed. prof, empl., workers	177 (51.3%)	84 (55.3%)	ns
managers, all levels	53 (15.4%)	14 (9.2%)	
maternal country of origin (n = 523)			
France	234 (62.4%)	100 (67.6%)	ns
other	141 (37.6%)	48 (32.4%)	
status of maternity unit (n = 574)			
private	178 (43.8%)	118 (70.2%)	p<0.001
public	228 (56.2%)	50 (29.8%)	
size of maternity unit (n = 576)			
≤500 births per year	14 (3.4%)	29 (17.1%)	
501 – 1000	45 (11.1%)	18 (10.6%)	p<0.001
1001 – 2000	190 (46.8%)	85 (50.0%)	
>2000	157 (38.7%)	38 (22.4%)	
Babies with DS placed for adoption (n = 593)	92 (22.6%)	23 (12.4%)	p<0.005

Table III

Characteristics of the 593 DS according to the parental decision on adoption.

Characteristics	Babies with DS given up for adoption n= 115	Total babies with DS n = 593	Babies with DS given up for adoption %	p value
sex (n = 592)				
male	49	294	16.7%	ns
female	66	298	22.2%	
birth rank (n = 495)				
1	47	207	22.7 %	p<0.05
2	28	141	19.9 %	
≥3	16	147	10.9 %	
major malformations requiring surgery (n = 590)				
yes	35	138	25.4 %	p<0.05
no	77	452	17.0 %	
maternal age (n = 574)				
15–24 years	7	72	9.7 %	p<0.05
25–29 years	24	119	20.2%	
30–34 years	43	165	26.1 %	
35–39 years	27	165	16.4 %	
40–54 years	5	53	9.4 %	
mother's occupation (n = 497)				
homemaker, no occup. Job	16	169	9.5 %	p=0.001
intermed. prof, empl., workers	55	261	21.1 %	
managers, all levels	18	67	26.9 %	
maternal country of origin (n = 523)				
France	82	334	24.6 %	p<0.001
other	21	189	11.1 %	
status of maternity unit (n = 574)				
public	51	278	18.4%	ns
private	63	296	21.3%	
size of maternity unit (n = 576)				
≤ 500 births per year	12	43	27.9 %	ns
501 – 1000	13	63	20.6 %	
1001 – 2000	52	275	18.9%	
>2000	36	195	18.5 %	

Table IV

Variables linked to the parental decision to give up for adoption (multivariate analysis)

Characteristics of the pregnancy	p value	odds ratio	95% CI
mother of foreign origin/French	p < 0.0001	0.36	0.19 – 0.67
resident in Marseilles area/Paris	p < 0.005	0.31	0.16 – 0.60
major malformation yes/no	p < 0.01	2.27	1.26 – 4.09
maternal age 15–24/other ages	p = 0.05	0.31	0.10 – 0.90
birth rank >2/other ranks	p < 0.05	0.49	0.25 – 0.94

Table V

Alternatives of placement for the 115 babies with DS given up for adoption

	adoptive families	foster families	public institutions
number of DS children	58/115 (50.4%)	41/115 (35.6%)	16/115 (14%)
age at placement			
< 6 months	28/58 (48.3 %)	7/41 (17.1%)	
6–12 months	18/58 (31.0%)	9/41 (25.3%)	
> 12 months	12/58 (20.7%)	25/41 (57.6%)	