

psychopathology in children in a developmental context. The next revision of the two systems of disease classification may contain categories with less pejorative and more accurate labels. Conduct disorders form the most common diagnostic group for children with DS (11%) and are almost as frequently found in the controls (10%). Hyperkinetic conduct disorder was more often found in the DS group (which appears to contradict the finding that hyperactive behaviour was significantly more often found in the controls). The psychotic children, often with histories of brain damage, in the control group had very high hyperactive scores.

Ineichen (1984) has questioned the findings of some studies on the prevalence of what has been termed 'mental illness' in retarded patients, particularly in hospitals. It is suggested that some at least of such 'illness' may be attributed to the poor environment or to failure to teach appropriate skills. Only a very small proportion of the children in our study were living in institutions; most of the children enjoyed family life as did their siblings. However, many of their disorders, particularly those grouped

rather unhappily as 'psychosis with origin specific to childhood: other', did appear to be related to the failure to communicate and to learn more acceptable ways of attracting attention or even passing time. Psychiatrists themselves have suggested that many children who are retarded do not need the attention of psychiatrists (Tarjan, 1977; Wortis, 1977), and these would include nearly one-third of all the subjects in this study. Nevertheless, a sizeable proportion of retarded children, just under 40% of those with DS but nearly half of the mixed group of similarly retarded controls, do have severe and distressing problems that require a broad range of psychiatric skills and understanding in order to make a valid diagnosis.

Behavioural and emotional problems are a serious secondary handicap for between four and five out of ten children with mental retardation and children with DS have nearly as many problems of this sort as other children similarly handicapped. There is, however, clearly a role, though not an exclusive one, for the psychiatrist in investigating and treating the problems described.

---

*British Journal of Psychiatry* (1986), **149**, 161–171

## Family Background of Children with Down's Syndrome and of Children with a Similar Degree of Mental Retardation

ANN GATH and DIANNE GUMLEY

The families of Down's Syndrome children and another group with a similar degree of retardation were compared using data collected at interview. Differences in social class distribution were explained by the maternal age effect in the Down's group. Divorce was more common in the control group but the quality of marriage in those parents still together and the health of parents were similar. No close associations were found between behaviour disorders in the children and family factors, except that behaviour disorders were likely to be associated with similar disturbance in siblings next in age and to be more common in the less happy marriages.

The literature concerning families of mentally retarded children is mostly concerned with the effect upon parents and siblings of the additional burden that bringing up a handicapped child imposes. Evidence from earlier studies was used to support the case for long-term hospital care; even families who

wanted to bring up the retarded child at home often felt themselves driven to request such care for their children because they could not cope with the demands upon them, (Oster & van den Tempel, 1975). The emphasis thereafter moved strongly to "community" care, and with more positive attitudes

to retarded children, including provision of education for all children, and some social support such as occasional relief care, more encouraging findings from research on families has appeared. One long-term study (Carr & Hewett, 1982) followed infants with Down's Syndrome (DS), originally investigated by Cowie (1970), to the age of 16, and found that a number of families were coping well and enjoying a good life in many ways. Similar positive findings were also noted in the follow-up of another group of children with DS first seen in infancy (Gath & Gumley, 1984).

There are, however, indications that some adverse effects on families occur quite early on, before the care of the child itself becomes very different from that of a normal child (Gath, 1977, 1978). These early effects are concerned with the 'value crisis' (Wolfensberger, 1968) which follows the initial shock, and occurs when the parents are forced to revalue many of their previous beliefs. Some marriages did not survive this revaluation, and others continued with deep rifts. Later effects, such as increased psychiatric morbidity in parents, shown when the children were aged eight or nine, are more related to what Wolfensberger called the 'reality crisis' and Tizard & Grad (1961) the 'burden of care'.

Recent research on families of mentally retarded children has moved from the negative approach of measuring what was assumed to be the inevitable stress upon other family members to looking at positive and negative effects in both directions. Strengths as well as weaknesses of parents and siblings are noted, particularly in relation to their ability to cope with not only the added work of caring for a more dependent child, but also the considerable demands of treatment. Objective measures of the way families actually live with a retarded child have now been developed. Bringing up such a child is extremely hard work, especially for the mother (Dupont, 1980; Wilkin, 1981; Pahl & Quine, 1984). Parents are now expected to take an active part in early education as well as in any physiotherapy or behavioural therapy which may be prescribed for the common additional problems. Even when these secondary handicaps become very severe, it is no longer common practice to admit the child for intensive therapy away from the family as the improvement often fails to generalise on discharge. Instead, the other family members are enrolled as co-therapists from the start and must learn and then continue the treatment programmes devised by professionals.

Our previous paper (Gath & Gumley, 1985), describes the behaviour problems in two groups of

retarded children, one with DS, which makes up the single biggest diagnostic group in special schools, and the other of children chosen by the teachers as having comparable verbal and physical abilities. Behaviour disorders were common in both groups, but slightly less so in the DS group. The present paper aims to compare the socio-demographic backgrounds of the two groups, and to look for factors particularly concerned with the presence of behaviour disorders in retarded children.

### Method

Children with DS were identified in schools in one Health region and were matched where possible with a similarly retarded child in the same class. The parents were interviewed in their homes using a semi-structured interview which was recorded on tape and coded by an independent rater. Part of the interview consisted of an assessment of the quality of the parents' marriage based on that devised by Brown & Rutter (1966) and used in previous studies of the families of retarded children (Gath, 1977, Gath & Gumley, 1984). A judgement was made of the quality of the marriage, particularly of the warmth and/or hostility evident throughout the interview. A further judgement was made of the state of mental health in both parents; this was based on the General Health Questionnaire (Goldberg, 1972) and on answers to questions concerning symptoms in the interview. Degree of incapacity was determined from the ability to work or to cope with home chores and the impression from the interview as a whole. This second judgement was agreed upon by the interviewer, the rater, and the first investigator.

Specific questions were asked about the sibling closest in age to the retarded child. Parents completed the Rutter A behavioural rating scale and, with their permission, teachers completed the Rutter B behavioural rating scale and a school report form.

As described by Gath & Gumley (1986), all the retarded children had been assessed on the American Association for Mental Deficiency Adaptive Behaviour scale (Nihira *et al.*, 1974). They had been divided into three groups—those with definite serious behaviour disorders, those with no behaviour disorder and a borderline group.

### Results

Family interviews had been carried out in the homes of 192 of the children with DS and 147 of the children with a similar degree of mental retardation.

*Age:* The mean age of the children with DS was 11.77 years with a range of 6–17. The mean age of the control children was 11.82 years.

*Home and parents:* One hundred and sixty-three (85%) of the children with DS lived at home with both natural parents. Thirty-one children with DS and 12 controls were

not living full-time with at least one natural parent. Three DS children were in boarding schools out of the region, but returned home for holidays and half terms. All the other children went to schools in the region, as did all the controls. Ten DS children and 3 controls were in the hostels run by the local authority, but usually went home for holidays and often for weekends as well. Comparable children were found as controls for four of the seven children with DS who were in long-stay hospitals for mentally handicapped patients. No suitable matches could be found for those in boarding schools. Three children with DS were adopted, as were two of the control children. Four families had made the adoption in the full knowledge of the child's retardation and associated medical diagnosis. The exception was one couple whose originally normal baby, adopted at three weeks, had suffered severe brain damage following encephalitis at the age of four. Eight DS children and 3 controls were in long-term foster care.

*Parents' understanding of the handicap:* Since DS is apparent from birth, there were marked differences between the two groups of parents as to when they first understood that their child had a handicap: 42% of the parents of the DS children said they knew immediately after the birth, and a further 30% said they knew during in the first week, compared with only 9% of the parents of the controls who had learnt by the end of the first week. Only 3% of the DS group felt they had not clearly understood about the handicap until after the first birthday, while 41% of the parents of the controls had learnt about it between the first and fifth birthdays, and in 9% of cases, the child had already reached compulsory school age before they knew.

All the parents of the DS group knew that their child had the syndrome or 'was a Mongol'. In 13 of the controls, there was no information about the parents' understanding of the child's handicap. Fifty (34%) thought the child had brain damage, 13 (9%) mentioned a specific syndrome, e.g. San Filippo disease, 53 (36%) had been told that there was no medical disorder but that their child was 'just generally backward' and 18 (12%) believed there was an underlying medical condition, as yet undiagnosed.

*Ethnic origin:* The majority (180, 93%) of the children with DS were Caucasian, with parents and grandparents born in the British Isles. Four were children of Caucasians from other European countries, five were children of Asian immigrants and five had parents born in the West Indies. The ethnic background of the control group was very similar, with four from other European countries, three from Asia and one from the West Indies.

*Family size:* The families in the Down's were larger than those in the control group, but the difference was not great. The mean sibship size in the Down's families was 3.44, with a range from one to ten, while that of the other families was 2.9, with a range of one to eight. Mean sibship size dropped from 4.0 in the families of the 16 year old children to 3.07 in families of the children aged 6-8 in the DS

group, but remained much the same in each age-group in the families of the controls. Fourteen DS children and 11 of the controls were only children, i.e. 11% of both groups.

Slightly fewer, 37 (22%) of the DS group, were first-born, compared with 53 (39%) of the control children. The mean ordinal position of the retarded child was 2.9 in the Down's group and 2.3 in the controls. Just over half the children with DS were the last born in the families, excluding only children, as were 63 or 46% of the controls.

*Social class:* There was a shift towards social classes I and II in the Down's as compared with the control group, ( $\chi^2 = 7.257$ , d.f. = 2  $P < 0.05$ ). The social class difference was insignificant in the children aged 12 or more, but was most marked in the youngest group, aged between six and eight at the time of assessment. The social class of 14 families in the DS group and of five families in the control group was not ascertained, as the fathers were either long dead or divorced, and their job status was unknown. Family size was related to social class in the control group only (Table I). Large families were common in all social classes in the DS group. There was a marked social class difference related to the parents' understanding of the nature of the child's developmental difficulties, with over-representation of social classes IV and V in the group who believed that there was no medical explanation for their child's retardation. The social class distribution of the DS group more closely resembled that of the families of the brain-damaged children or of those with specific syndromes.

*Maternal age:* Mothers of the children with DS were older at the time of the birth than were those of the controls, the mean ages at the time of the birth being 33.53 and 28.03. The age gap was greatest in the small group where the social class of the father was unknown. As expected, mothers who had been aged 40 or more at the birth of the retarded child were much more common in the DS group, numbering 58 (28%) as against only seven (5%) in the control group ( $\chi^2 = 29.3$  d.f. = 1,  $P < 0.001$ ). By contrast, there were 13 (9%) young mothers aged 20 or less at the birth of the child in the control group, and six (3%) in the Down's group, ( $\chi^2 = 4.14$ , d.f. = 1,  $P < 0.05$ ). The mean age of mothers and the total family size tended to be less in the younger groups of children. Mothers of DS children were more likely to have done well at school and to have had further education: 26 mothers of DS children had had professional training, particularly as nurses or teachers, and ten had a university degree, compared with ten and two respectively of the control mothers, ( $\chi^2 = 15.37$ , d.f. = 3,  $P < 0.001$ ).

*Marital relationship of the parents:* The natural parents were no longer together in 32 families in the DS group and in 35 families in the control group. There were nine widows and one widower in the Down's group and six widows in the control group. Twenty-three marriages were broken by divorce in the control group, but only ten in the DS group,

TABLE I  
Family size and social class

Family size	Down's syndrome				Total
	I & II	III	IV & V	Not known	
1	6	5	2	1	14
2 or 3	46	42	20	1	110
4 or more	16	28	14	11	68
Total	68	75	36	13	192

( $\chi^2 = 4.943$ , d.f. = 4, NS)

  

Family size	Controls				Total
	I & II	III	IV & V	Not known	
1	3	6	2	0	11
2 or 3	27	46	22	3	98
4 or more	3	17	16	2	38
Total	33	69	40	5	147

( $\chi^2 = 9.3328$ , d.f. = 4,  $P < 0.02$ )

( $\chi^2 = 7.3$ , d.f. = 1,  $P < 0.05$ ). There was no significant difference between the quality of the marital relationship in those families where the natural parents were still living together. In four of the DS group and one of the controls, no information was available on the natural parents. Good marriages were evenly distributed throughout the social classes in both groups, but very poor marriages tended to be more frequently found in social classes IV and V.

*The health of the parents:* The physical health of the mothers was considered to be a problem in 17% of the families of DS children and 13% of the families of controls. A similar degree of concern about the fathers' health was expressed by 15% of families of DS children and by 12% of controls. Many mothers described themselves as suffering from 'nerves', but there were slightly more of these in the control group—42% as opposed to 39%. Fathers were less commonly affected by 'nerves'—22% of the control group and 14% of the Down's group. Scores of ten or more on the General Health Questionnaire were obtained from seven mothers and two fathers in the Down's group and six mothers and seven fathers in the control group.

Severe mental illness (incapacitating, necessitating admission to a psychiatric hospital and/or inability to cope for at least a month in the past year) affected 2.8% of the whole group of parents and was evenly distributed among mothers and fathers in both groups. There was one case of manic-depressive psychosis in the DS group and one case of schizophrenia in the control group. The remainder of the affected parents suffered from depression (Table II). Minor disorder, causing distress and some impairment of

TABLE II  
Mental health status of parents of Down's syndrome children and controls

	Well	Minor disorder	Severe	Total
<i>Mothers</i>				
Downs syndrome	130	41	5	176
Controls	105	29	4	138
Total	235	70	9	314
<i>Fathers</i>				
Downs syndrome	125	17	3	145
Controls	93	17	4	114
Total	235	34	7	259

Down's Syndrome v. controls:

Mothers:  $\chi^2 = 0.2325$ , d.f. = 2, NS

Fathers:  $\chi^2 = 1.1461$ , d.f. = 2, NS

Mothers v. Fathers:

Down's syndrome:  $\chi^2 = 7.606$ , d.f. = 2,  $P < 0.05$

Controls:  $\chi^2 = 1.585$ , d.f. = 2, NS

the capacity to cope, was found in twice as many mothers as fathers in both groups. There were few differences between the groups, but despite more mothers of the controls reporting problems with 'nerves', a clinical psychiatric disorder was judged to be present slightly more often in the mothers of the DS group. A mixture of anxiety and depressive symptoms was reported in most cases. In all, 46 mothers and 20 fathers in the DS families were judged as

TABLE III  
Psychiatric disorder in parents and quality of parents' marriage

	Marriage rating				
	Good	Moderate	Poor	Widowed	Divorced
<i>Down's syndrome</i>					
Parents with psychiatric disorder	9	25	10	2	7
Both parents well	82	32	1	8	5
Total	91	57	11	10	12
<i>Controls</i>					
Parents with psychiatric disorder	13	14	9	2	8
Both parents well	46	35	0	4	15
Total	55	49	9	6	23

having a psychiatric disorder. In 12 families, both parents were affected; 33 mothers and 21 fathers in the control group had a psychiatric disorder, with both parents affected in eight families. Psychiatric disorder in the parents of both groups of children was closely correlated with the quality of the parents' marriage (Table III).

At least one parent, but in many cases both, had a psychiatric disorder in ten of the eleven most disharmonious marriages in the Down's group and in all the very poor marriages in the control group. Widowed and divorced mothers, by contrast, were not particularly vulnerable in this respect. Psychiatric disorder showed a gradual increase with social class. In class I, 19% of the children with DS and 20% of the controls had a parent with psychiatric disorder. The percentages of affected families in social classes IV and V rose to 30% for DS and 35% for the controls. Psychiatric disorders was not more common in older mothers.

*Brothers and sisters:* There were 99 siblings in the DS families and 92 in the families of the control children who were still at school and aged within five years of the retarded child. Eleven (11%) of the siblings of the DS children were regarded by their parents as having significant problems and 12 (13%) of the control siblings. The ratings made by the parents were very similar to those on the Rutter A scale where five boys and six girls in the DS group and seven boys and four girls in the control families had high scores. More siblings, 15 boys and eight girls, in the families of the controls had high scores on the Rutter B behavioural scale, as rated by the teachers, compared with nine brothers and eight sisters of the DS children. There were no significant differences between brothers and sisters or older or younger siblings in either group. Behaviour disorder in the siblings was closely related to that of the retarded children in the families of DS children but not in the families of the controls, (Table IV).

TABLE IV  
Disorder in the retarded child and disorder in siblings

	Normal siblings		Total
	With behaviour problem	No behaviour problem	
<i>DS children</i>			
With behaviour problem	18	22	40
No behaviour problem	6	53	59
Total	24	75	99
$\chi^2 = 13.9075$ , d.f. = 1, $P < 0.001$			
<i>Control children</i>			
With behaviour problem	16	27	43
No behaviour problem	15	34	49
Total	31	61	92
NS			

*Practical aspects of family life:* Very few families employed paid help. The eight who did have paid help all came from the DS group; five were from social class I and three from class II. More families in the control group depended upon a grandmother of the child for help: 35 (24%) of the controls and 27 (14.5%) of DS children had grandmothers who were a regular and important source of help ( $\chi^2 = 4.087$  d.f. = 1,  $P < 0.05$ ). Sixty-one (33%) of the families of the DS children were helped regularly by a neighbour or friend, compared with 33 (22%) of the families of the controls ( $\chi^2 = 3.84$ , d.f. = 1  $P < 0.05$ ).

Slightly fewer in the control group of families (48%) had regular annual holidays than did the families in the

DS group (58%). Similar numbers went on family trips altogether or the parents went out as a couple. Only 8% of each group felt they had major problems making baby-sitting arrangements.

*Support services:* During the pre-school years, the family doctor and health visitor provided most support, and despite the more regular contact of the health visitor, parents were more appreciative of the help offered by the doctor. A significant minority, 29%, in both groups, could name no reliable source of help or advice when their children were small. Once the child had gone to school, more (21%) of the parents in the DS group still felt they had no one to turn to, compared with 12% of the control parents. The doctor's involvement did not lessen although in 15% of cases the school staff were rated as equally important. The teachers were consulted about problems almost as frequently as doctors, and a fifth of the parents regarded them as the main source of help with the retarded child. Social workers were seen as closely involved in less than 3% of all the families.

The majority of parents, more than 80% in each group, felt that the school concerned was the right one for their child's particular needs. Relief care was available for the families. 44% of both groups of families used hostels, of which there was at least one in each county. Slightly more, (25, 13%), of the DS children went to a hospital for relief care than did the controls (12, 8%). Half of the parents were very appreciative of the relief care available, finding it provided a useful break for them and often a good experience for the child. However, 30% of both groups of parents were clearly dissatisfied with the services provided for their children.

*Pre-school education:* The pre-school educational opportunities for the children were different in the groups: 89 DS children and 37 controls had been to either a play group specifically for handicapped children or a nursery in a special school ( $\chi^2 = 15.35$ , d.f. = 1,  $P < 0.001$ ). Conversely, 70 of the controls and 55 DS children had been to an ordinary play group, catering for normal children ( $\chi^2 = 10.67$ , d.f. = 1,  $P < 0.01$ ). However, an additional 17 DS children and four controls had had the advantage of both sorts of pre-school provision.

Early intervention for handicapped children had only just become available when these children were small: 11 of the DS children and eight of the controls had been visited regularly by a teacher or counsellor in the first five years. None of the DS children who had had some early intervention had adaptive behaviour scores significantly below the average for the age-group but four had behaviour disorders and a further four were in the borderline group. The children in the control group given early intervention included three multi-handicapped children with very low adaptive behaviour scores and much deviant behaviour: only one child in this group had no behaviour problems.

*Adaptive behaviour and parental psychiatric illness:* Parents with psychiatric disorder were not more commonly found

in those families where the child had very low AAMD Adaptive Behaviour scores. Neither was additional physical disability, indicated by a low score on the physical development sub-scale, nor a low language score associated with a higher incidence of parental psychiatric illness.

*Parents' perception of behaviour problems in the retarded child:* The parents thought that 29 (15%) of the DS children and 37 (25%) of the controls had significant behaviour problems. These figures are much lower than the numbers of children judged as having serious behaviour disorder from the rating scales and behavioural check-lists. Hyperkinetic or bizarre behaviour were the most likely types to have been seen as problems by the parents, but they were not especially likely to see the children with very low adaptive behaviour as also having behaviour problems. Mothers with psychiatric disorder themselves were more likely to perceive their DS children as having significant behaviour problems, but this was not so in the control group. In the borderline group, there were four DS children identified by parents as having significant problems and two others in the group judged as normal. Three judged as 'borderline' and two as 'no disorder' in the control group were considered by their parents to have behaviour problems.

*Factors associated with behaviour disorders:* Behaviour disorder in the retarded child, as defined in the previous paper, were not related to family size, to age or educational achievements of the mother, to the physical health of either parent, or to relationships with members of the extended family. Neither was there evidence of association with social class, since the frequency of definite disorder was not significantly different in any social class in either group.

Three of the seven Down's children and three out of the four control children in the long-stay hospitals were found to have serious behaviour disorders. Disturbance was common also among those in local authority hostels, in five out nine DS children and in all three controls in hostels. By contrast, only one in eight of the fostered and one of the three adopted DS children had serious behaviour disorder. The adopted and fostered control children had more behaviour disorder, affecting all but one fostered child.

*Behaviour disorders in the children and psychiatric disorder and quality of marital relationship of parents:* Behaviour disorders in the controls were more frequent in the children whose parents' marriage was rated as moderate or poor than in those where it was rated as good (Table V). The same trend, to a lesser degree, could be seen in the DS families. There were fewest behaviour disorders in DS children of widowed or divorced mothers, with a clear difference between them and the children where the marriages were rated as moderate or poor, ( $\chi^2 = 4.63$ , d.f. = 1,  $P < 0.05$ ). In the control group, the highest rate of disorder was found among children of widows, the rate in the

TABLE V  
Disorder in the retarded child and quality of the marital relationship between parents

	Good	Quality of marriage Moderate	Poor	Total
<i>DS Children</i>				
Definite disorder	33 (36%)	26 (46%)	6 (55%)	65
Borderline/no disorder	58	31	5	94
Total	91	57	11	159
	$\chi^2 = 2.18, d.f. = 2, NS$			
<i>Control children</i>				
Definite disorder	19 (35%)	24 (49%)	7 (77%)	50
Borderline/no disorder	36	25	2	63
Total	55	49	9	113
	$\chi^2 = 6.645, d.f. = 2, P < 0.05$			

TABLE VI  
Disorder in the retarded child and psychiatric disorder in the parents

	Parents' mental health		Total
	One or both parents with severe disorder	Parents well mild disorder	
<i>Down's group</i>			
Disorder in retarded child	4	16	54
Borderline or no disorder in retarded child	4	28	86
Total	8	44	140
<i>Control group</i>			
Disorder in retarded child	6	17	48
Borderline or no disorder in retarded child	21	54	76
Total	7	38	102

(Down's  $\chi^2 = 0.5316, d.f. = 2, NS$ )

(Controls  $\chi^2 = 4.1802, d.f. = 2, NS$ )

divorced group being very similar to that found in association with poor marriages. Parental psychiatric disorder was most common in social classes IV and V, affecting 30% of families so classified in the DS group and 35% of families in the control group. Behaviour disorders in the retarded children in these social classes occurred just as commonly in families with well parents as in families with a psychiatrically ill parent. Psychiatric illness in the parents was likely to be associated with a poor marriage relationship. In the DS families with a good marital relationship,

parents with psychiatric disorder were more likely to have a retarded child who had a behaviour disorder, although the numbers in this group were small. In the context of a moderate or poor marriage, there was no demonstrable association between parental psychiatric disorder and behaviour disorders in the DS children themselves. Similarly, there was no strong association of parental psychiatric illness with behaviour disorders in the control group, except where there was severe mental disorder in the mother or father (Table VI).

### Discussion

There was greater maternal age and a higher level of maternal education, with a bias towards upper social class, in the families of the children with DS. In this study, the older mothers included a significant proportion of women with degrees or professional training which had necessitated postponement of child bearing. Younger children with DS tended to come from smaller families, unlike those formerly typical—usually in social classes IV and V—where a child with DS would be born at the end of a long sibship. The social class distribution of our controls did show an opposite bias towards social classes IV and V, as has been reported in other recent studies of the family background of retarded children (Cooper & Lackus, 1984).

We found no evidence that older mothers were more vulnerable than younger ones, or that they were less effective in rearing these difficult children. There was less support from grandmothers in the DS group, which can be explained on grounds of age, as these older mothers did not themselves have mothers capable of offering them support.

The comparatively easy recognition of DS influences decisions made not just by the families themselves but by the community on how the child is reared, as is seen in the preschool period. The children are set off on a different pathway early in life, long before any objective measure can be made of the extent of intellectual impairment.

There is little evidence from this study to support the idea that bringing up a child with DS is markedly less stressful than rearing one with mental retardation due to other causes, although indications of other social problems were seen in the control families. No large differences in morbidity emerged among the parents in the two groups. Divorces were more common in the control group, although the quality of those marriages where husband and wife remained together differed little.

The incidence of psychiatric disorder in both groups of fathers was not markedly higher than that found in the general population, of whom 10.9% in surveys using the PSE have sufficient symptoms to be regarded as 'cases' (Wing *et al.* 1981). The higher incidence in the mothers can be interpreted as supporting the theory that they carry most of the burden and show most ill-effects. However, even the finding of 24% is not dissimilar to those of maternal disorder in families bringing up normal children under difficult circumstances (Brown & Harris, 1978; Richman *et al.* 1982).

Unhappy marriages are clearly associated with psychiatric disorder in parents in this group, and

both adverse effects occurred most frequently in the socially deprived families, in social classes IV and V. A mentally retarded child and an unhappy marriage in poor social circumstances add up to a high level of adversity (Pahl and Quine, 1984). There is a stronger association between behaviour disorders in the retarded child and marital discord in the control group than in the DS group.

The two groups of siblings of handicapped children had very similar rates of disturbance at home, but there was a difference, although not a large one, at school where the siblings of the control group were more often rated as deviant. An earlier finding, (Gath, 1974) that older sisters were particularly vulnerable has not been replicated in this study, ten years later. At that earlier time, their vulnerability was thought to be possibly due to the excessive burden of domestic responsibility. Improvements in provision for mentally retarded children may have contributed to the disappearance of sisters as a particularly vulnerable group, but in the 1974 study of siblings, 14 out of 89 sisters (16%) and 22 out of 85 brothers (26%) of children with DS were rated as deviant, using the same behavioural rating scales. In the present study, deviant scores were obtained by 25% of sisters and 23% of brothers. An alternative explanation might be that over the years, deviancy among all girls, including the sisters of DS children, has caught up with that previously found only in boys.

The behaviour disorders in the DS children showed a close association with psychiatric disorder in the siblings, as defined by deviant scores on either of the two Rutter scales. However, no such association was noted in children and siblings in the control group. A more detailed comparison of the retarded child/sibling pairs will be the subject of a further paper.

Parents appeared to show a remarkable degree of tolerance towards abnormal behaviour in their retarded children. Using objective measures, many more children were found with serious behaviour disorders than had been identified as such by their parents. Many parents regarded behaviour difficulties as an integral part of the handicap, and their attitude was one of resignation rather than tolerance. Psychiatrically disordered mothers of DS children did tend to perceive their children as having behaviour problems, whether they actually had them or not.

In child psychiatric literature, the association between parental psychopathology and childhood psychiatric disorder is well known. Various explanations have been suggested—genetic, based on family studies (Crowe 1983) and adoption studies

(Bohman, 1978) and environmental, the latter with particular emphasis on the effects of marital discord which often accompanies parental psychopathology (Quinton & Rutter, 1985). Most published work on families of handicapped children, particularly those who are mentally retarded, looks at the problem from the opposite point of view—that the child's disturbing behaviour is the cause of 'stress' to the parent, and hence of the symptoms, both physical and mental, which may result. Stress in our DS families is shown by the mother's perception of the child's behaviour as a problem.

Behaviour disorder in the DS child in this study was as common in social class II as in IV and V. This certainly does not fit with the findings on children in the normal range of intelligence, and is more in keeping with the hypothesis that in families with a retarded child the development of a behaviour disorder in that child is related to factors within the child rather than to environmental influences, especially within the family. A retarded child with a behaviour disorder in the home is certainly stressful, but psychiatric disorders in the parents studied by us, particularly the mothers, bore no simple relationship to the presence of behaviour disorder in the child, any more than they did to other measures of handicap. Other social problems compound this issue in the most deprived families, where the greatest ill-health and marital misery is found, but different factors must be operating in classes I and II.

The longitudinal study (Gath, 1977) showed that effects on a marriage occurred very soon after the birth of a child with DS and our follow-up of the families of children first seen in infancy indicates that behaviour disorders are likely to develop in families which have long-standing problems. In the present study, families where both parents were well and had a good harmonious marriage were in the minority in both DS and control groups, but where they occurred, they did so irrespectively of the ages and sexes of the affected children.

However, family influences alone can by no means explain the development of behaviour disorder either in children with DS or in controls. In the longitudinal study, communication problems with marked speech delay were found to be closely related to behaviour disorders, as also was general severe retardation. Both groups of children in this present study have been assessed using Adaptive behaviour scales and more detailed psychological testing of the DS children has also been carried out. These findings will be further analysed in relation to behaviour disorders in a later paper.

### Conclusion

The family backgrounds of children with Down's syndrome have somewhat different socio-demographic features from those of other children with a similar degree of intellectual retardation. These differences can be summed up as a bias towards relative social advantage and easy parental recognition of the handicap in contrast to an opposite bias towards social deprivation and parental uncertainty in the control group whose retardation resulted from various known and unknown causes.

In our previous paper, the myth of the child with DS being an easy child was found not to be valid, so the apparent advantage of early diagnosis and the higher chance of being born to more educated parents does not spare the majority of families from the initial grief or long years of very hard work involved in rearing them. Marital discord is common and is associated with behaviour problems in the retarded child. This was even more true in the families of our control children than in families of those with DS. The finding that psychiatric morbidity is higher than in the general population in mothers, but not in fathers, in both groups suggests that the carer, usually the mother, has a heavy burden and is at risk of developing psychiatric disorder. That the risk is much the same for other women rearing children in difficult circumstances does not detract from the importance of this finding, since the others are likely to improve as their children grow up, whilst mothers of mentally handicapped children will face an even greater problem as their children leave school but not home. The options are least for those children who are doubly handicapped by difficult behaviour as well as mental retardation. Families who would be able to cope adequately with the demands of ordinary family life are now being asked to take on an exceptional role with no time off for an indefinite period. Even the most stable and healthy families require more help from outside than is easily available at present. Those with additional problems will need the services even more desperately but may be less able to obtain the help to which they are entitled. Services, therefore, must be sufficiently flexible to be able to respond to individual needs but this must not be at the expense of either the self-respect of the family or the well-being of the child.

### Acknowledgements

This work was supported by a grant from the Medical Research Council. We should like to thank Kath Blow, Terry Lewis and Andrew Clarke for their help.

## References

- AMERICAN PSYCHIATRIC ASSOCIATION (1980) *Diagnostic and Statistical Manual of Mental Disorders* (3rd edition, DSM-III). Washington, D.C.: American Psychiatric Association.
- BIRCH, H. G., RICHARDSON, S. A., BAIRD, D., HOROBIN, G. & ILSEY, R. (1970) *Mental subnormality in the Community: A Clinical and Epidemiologic Study*. Baltimore: Williams & Wilkins.
- BOHMAN, M. (1978) Some genetic aspects of alcoholism and criminality. A population of adoptees. *Archives of General Psychiatry* **35**, 269–276.
- BROWN, G. W. & RUTTER, M. (1966) The measurement of family activities and relationships—a methodological study. *Human Relations* **19**, 241–263.
- & HARRIS, T. (1978) *Social Origins of Depression: a Study of Psychiatric Disorder in Women*. London: Tavistock.
- CARR, J. & HEWETT, S. (1982) Children with Down's syndrome growing up. *Association for Child Psychology and Psychiatry News* **10**, 10–13.
- CHESS, S. (1977) Evaluation of behaviour disorder in a group of mentally retarded children. *Journal of the American Academy of Child Psychiatry* **16**, 5–13.
- & HASSIBI, M. (1970) Behaviour deviations in mentally retarded children. *Journal of the American Academy of Child Psychiatry* **9**, 282–297.
- COOPER, B. & LACKUS, B. (1984) The social class background of mentally retarded children. A study in Mannheim. *Social Psychiatry* **19**, 3–12.
- CORBETT, J. (1977) Studies of mental retardation. In *Epidemiological Approaches in Child Psychiatry* (ed. P. J. Graham) London: Academic Press.
- COWIE, V. A. (1970) *A Study of the Early Development of Mongols*. Institute of Research in Mental Retardation Monograph No. 1., London: Pergamon.
- CROWE, R. (1983) Antisocial personality disorders. In *The Child at Psychiatric Risk* (ed. R. E. Tarler), 214–277. Oxford: Oxford University Press.
- DUPONT, A. (1980) A study concerning the time-related and other burdens when severely handicapped children are reared at home. In *Epidemiological Research as Basis for the Organization of Extramural Psychiatry*. *Acta Psychiatrica Scandinavica*, **62**, Supplement **285**, 249–257.
- GATH, A. (1974) Sibling reactions to handicap—a comparison of the brothers and sisters of mongol children. *Journal of Child Psychology and Psychiatry* **15**, 187–198.
- (1977) The impact of an abnormal child on the parents. *British Journal of Psychiatry* **130**, 405–410.
- (1978) *Down's Syndrome and the Family: the Early Years*. London: Academic Press.
- & GUMLEY, D. (1984) Down's syndrome and the family: follow up of children first seen in infancy. *Developmental Medicine and Child Neurology* **26**, 500–508.
- , — (1985) Behaviour problems in retarded children with special reference to Down's syndrome. *British Journal of Psychiatry* **149**, 156–161.
- GIBBS, M. V. & THORPE, J. G. (1983) Personality stereotype of noninstitutionalised Down's syndrome children. *American Journal of Mental Deficiency*, **87**, 601–605.
- GIBSON, D. (1978) *Down's syndrome: the psychology of mongolism*. Cambridge: Cambridge University Press.
- GOLDBERG, D. P. (1972) *The Detection of Psychiatric Illness by Questionnaire* Maudsley Monograph no. 21. Oxford: Oxford University Press.
- GRODEN, G., DOMINGUE, D., PUESHEL, S. M. & DEIGNAN, L. (1982) Behavioural/emotional problems in mentally retarded children and youth. *Psychological Reports*, **51**, 143–146.
- GUNN, P. & BERRY, P. (1985) The temperament of Down's syndrome toddlers and their siblings. *Journal of Child Psychology and Psychiatry* **26**, 973–979.
- INEICHEN, B. (1984) Prevalence of mental illness among mentally handicapped people: discussion paper. *Journal of the Royal Society of Medicine* **77**, 761–765.
- KAMINER, R. K., JEDRYSEK, E. & SOLES, B. (1984) Behaviour problems of young retarded children. In *Perspectives and Progress in Mental Retardation: Vol. II. Biomedical Aspects* (eds J. Berg & J. M. de Jong) Baltimore: University Park Press.
- KOLLER, H., RICHARDSON, S. A. & KATZ, M. (1983) Behaviour disturbance since childhood among a 5-year birth cohort of all mentally retarded young adults in a city. *American Journal of Mental Deficiency* **87**, 386–395.
- KUSHLICK, A. (1975) The rehabilitation or habilitation of severely or profoundly retarded people. *Bulletin of the New York Academy of Medicine*, **51**, 143–161.
- MENOLASCINO, F. (1970) Down's syndrome: clinical and psychiatric findings in an institutionalised sample. In *Psychiatric Approaches to Mental Retardation* (ed. F. Menolascino). New York: Basic Books.
- NIHIRA, K., FOSTER, R., SHELLHAAS, M. & LELAND, H. (1974) A.A.M.D. Adaptive Behaviour Scale, 1974 Public School Revision. *American Association for Mental Deficiency*, Washington, D.C.
- OSTER, J. & VAN DEN TEMPEL, A. (1975) A 21 year psycho-social follow up of 524 unselected cases of Down's syndrome and their families. *Acta Paediatrica Scandinavica* **64**, 505–513.
- PAHL, J. and QUINE, L. (1984) Families with mentally handicapped children: a study of stress and of service response. *Report, Health Services Research Unit*, University of Kent.
- PHILIPS, I. & WILLIAMS, N. (1975) Psychopathology and mental retardation: a study of 100 mentally retarded children: I, Psychopathology. *American Journal of Psychiatry*, **132**, 1265–1271.
- QUINTON, D. and RUTTER, M. (1985) Family pathology and child psychiatric disorder: a four year prospective study. In *Longitudinal Studies in Child Psychology and Psychiatry: Practical Lessons from Research Experience* (ed. A. R. Nicol) Chichester: John Wiley.
- REID, A. H. (1980) Psychiatric disorders in mentally handicapped children: a clinical and follow-up study. *Journal of Mental Deficiency Research*, **24**, 287–298.
- RICHMAN, N., STEVENSON, J. & GRAHAM, P. (1982) *Pre-school to School. A Behavioural Study*. London: Academic Press.
- RUTTER, M. (1971) Psychiatry. In *Mental Retardation. An Annual Review* (ed. J. Wortis). New York: Grune & Stratton.
- , TIZARD, J. & WHITMORE, K. (1970) *Education, Health & Behaviour*. London: Longman.

- SMITH, G. F. & BERG, J. M. (1976) *Down's Anomaly*. Edinburgh: Churchill Livingstone.
- STEIN, Z. & SUSSER, M. (1975) Public health and mental retardation: new power and new problems. In *The Mentally Retarded and Society* (eds M. J. Begab & S. A. Richardson), Baltimore: University Park Press.
- SZYMANSKI, L. S. (1980) Psychiatric diagnosis of retarded persons. In *Emotional Disorders of Mentally Retarded Persons* (eds L. S. Szymanski & P. E. Tanguay), Baltimore: University Park Press.
- TANGUAY, P. E. (1984) Toward a new classification of serious psychopathology in children. *Journal of the American Academy of Child Psychiatry*, 23, 373-384.
- TARJAN, G. (1977) Mental retardation and clinical psychiatry. In *Research to Practice in Mental Retardation*, vol. I., *Care and Intervention* (ed. P. Mittler), Baltimore: University Park Press.
- TIZARD, J. & GRAD, J. (1961) *The Mentally Handicapped and their Families*. Maudsley Monograph no. 7. London: Oxford University Press.
- WEBSTER, T. G. (1970) Emotional development in mentally retarded children. In *Psychiatric Approaches to Mental Retardation* (ed. F. Menolascino), New York: Basic Books.
- WILKIN, D. (1981) A task oriented approach to the assessment of the distribution of the burden of care, levels of support and felt needs in the family. In *Assessing the Handicaps and Needs of Mentally Retarded children*. (ed. B. Cooper) London: Academic Press.
- WING, J. K., BEBBINGTON, P., HURRY, J. & TENNANT, C. (1981) The prevalence in the general population of disorders familiar to psychiatrists in hospital practice. In *What Is A Case? The Problem of Definition in Psychiatric Community Surveys* (eds J. Wing, P. Bebbington & L. N. Robins) London: Grant McIntyre.
- WOLFENBERGER, W. (1968) Counselling the parents of the retarded. In *Mental Retardation: Appraisal, Rehabilitation and Education* (ed. A. A. Baumeister) London: University of London Press.
- WORLD HEALTH ORGANISATION (1978) *Mental Disorders: Glossary and Guide to their Classification in Accordance with the Ninth Revision of the International Classification of Diseases (ICD-9)*. Geneva: World Health Organisation.

\*Ann Gath, DM, MRCPsych, DCH, *Consultant Child Psychiatrist, The Drummond Clinic, West Suffolk Hospital, Bury St. Edmunds, Suffolk, IP33 3PP.*

Dianne Gumley, MA, *Senior Research Psychologist.*

\*Correspondence

(Accepted 3 January 1986)